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ABSTRACT

The mother of a child with spina bifida recounts her difficulties in trying to obtain services for her disabled son. She touches on such topics as her feelings on being told her infant was disabled, treatment by medical personnel, reactions of family and friends, home therapy with the Doman Delacato patterning program, testing and evaluation, problems in enrolling her child in school, impressions of a state institution, efforts in fund raising, and organizations dealing with the disabled and their parents. Vignettes illustrate the way society discriminates against the disabled and the need for parents to take the role of child advocate. (SBH)

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STICKS AND STONES

the Story of Loving a Child

by Elizabeth Pieper

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Chapter One
Jeff's Birth

I lay on my back, the heat pressing in on me. For a fleeting moment a vague rememberance of other days, when I was young and full of dreams, passed over me and was quickly gone. I realized with some detached sense of shock that I had not felt a comfortable, lethargic glow since I lay on my single bed, long ago, with the seersucker of summer pressing its pattern into my moist and youthful skin. Somewhere, in between, there lay another day—hot, humid, and pregnant with foreboding which had separated me forever from that laughably naive and passionate girl.

Certainly I had regarded extreme heat with annoyance and suspicion for years now. Suddenly it was easy to remember that day, to view it as one does a dream, at once participating, seeing, hearing, feeling, smelling, and at the same time observing dispassionately as if one were, after all, only a quavering spirit on one's way to other affairs of more importance, momentarily detained by idle curiousity. Then I lay on my back with heavy, rough hospital sheets drawn tersely across my breast. In spite of the terrible heat, I was cold and alone. I had just given birth to our first baby, a boy whom I had named early in my pregnancy. Jeffrey. Jeffrey of my hopes and dreams!

I was, of course, the object of much good-natured teasing for my stubbornness. However, there had not been the least doubt in my mind that God would provide me with a son, and that in gratitude, I would, like Hannah, turn him back to the Lord that we might all serve and love our Maker and live happily ever after. This, too, was one of the secret dreams of torpid summer days.

The heavy door of the delivery room opened and a nurse's aid came in. I had scarcely said, "Hi," when she mounted a stool, leaned high over me, and swiftly plunged both fists hard and deep into my tender abdomen. My impulse was to smack her. "What was that for?" I asked in utter awe.

"We're after clots," she offered briskly. She took my legs out of the stirrups and pulled the stained white leggings off. "Thank God," I thought. My legs were cold and numb. As she washed me and placed a sanitary pad between my legs, I thought casually how peculiar and embarassing, how unnatural it seemed to have someone performing these intimate tasks.

"I had my baby without anesthesia," I said, afraid that she might leave me. "I thought I'd be able to hold him right away," I hastened on in order to detain her. She really was not much interested. Or perhaps she simply thought that I was painfully ignorant of hospital policy.

"I don't know nothin' about it. Don't ask me." With her arms full of paraphernalia, she rolled her backside around the heavy door, keeping it open until she disappeared. "I don't know nothing about it," her voice reiterated. The heavy door swung slowly shut behind her.

I lay once again, looking up at the ceiling with its mass of chipped green pipes running crazily in every direction. I busied myself selfconsciously with every senseless detail. Finally I felt the weight of isolation. Somehow I had the sense of doing something wrong. It was clear that I was not supposed to ask questions, so that even when someone was with me, I was alone in the most awful way. And when I was alone, it was worse.

Before Jeff's birth, I had valued my privacy. I had waited until the last possible moment before going to the hospital. I had toyed with the idea of having my baby at home. However, there were no provisions to do such a thing under medical sanction. The nurse who gave our preparatory course in childbirth was, in all probability, actually distressed at the reality of natural childbirth and included the exercises as a young parent does fairy tales, not entirely convinced of their value, but secretly fascinated with their morbid overtones.

In 1961, at least in our part of New York, birth was primarily the province of the physician. The women were usually "out," with a few brave souls who wanted to see their babies born having caudals or "spinal blocks" so that they would not feel the pain. Husbands were invited to a film or hospital tour on one night as part of the course which was to prepare them for the actual delivery. They were not allowed in the delivery rooms, but were familiarized with the business office.

Therefore, Carl's reaction was probably typical, given the expectancy of the day. When he came home from lunch and found that I was in labor, he became as restless as I. Although he was excited, he seemed relieved when I sent him back to work promising to call if I should be sent to the hospital.

Even among women, my desire to see my baby born was regarded as unorthodox. When I mentioned my hope in our sewing circle, the women demurred with mock horror as if I'd produced a lumpy toad. I could not tell if they honestly felt that it was uncomely to participate fully in birth, or whether, they too, were simply behaving as they felt they should.

Still, the experience I had had was enviable and never to be forgotten. Nothing I had read or heard could have prepared me for it. I was anxious to share every detail with Carl. I wondered impatiently why he did not come.

It was all so extraordinary. Yesterday I had felt depressed with the closing of August, as if somehow in spite of my great, round belly, I had blown my chance. I was already late and it was easy to think that it was all over even if nothing had happened. Finally I fell asleep, deeply disappointed. But when my early morning trip to the bathroom did nothing to relieve the gathering pressure, I went hopefully back to bed and to an idle sleeplessness.

I awoke at eight to find Carl already gone. Another trip to the bathroom produced a bright clean spot of blood. I was elated and called out in exuberance to an empty house, "Today Momma gets you, Jeff," Almost uncomprehendingly, I realized, "Today is your birthday. Today I'm a mother."

My exuberance faltered with the terrific cramps and cold chills that gripped me erratically. There was no pattern and no sense to be made of timing my contractions. Sometimes they would last for five minutes, sometimes for twenty-five minutes. Likewise, of course, the intervals of blessed and unique relief in between were unpredictable. I managed to wash and set my hair. I finished packing my suitcase. A diaper service man chose this time to pay a visit, explaining everything from how the deodorizer worked to the various ways to fold a diaper.

I called Dr. Jackson and took a 2:30 appointment. After pacing like a caged animal, doing the breathing exercises as best I could remember, and trying to swallow a shot of whiskey straight, I called my mother to see if she would take me to the doctor's office a little early. I could have driven there myself if the chills had not doubled me over. Paradoxically it was a hot, humid 91 degrees, the hottest day of the summer and unusual for September 1 in upstate New York.

The office was crowded with people, but the nurses worked me in early. Dr. Jackson, a sunny, warm man beamed at me.

"You've done a lot better than I expected," he said. "Tell your mother to get you to the hospital, and don't bother too much about the lights." He was grinning broadly. As we left, I looked again around the room full of women who would have to wait while my baby was born.

As we passed slowly in front of a dairy store, I saw children licking at fast-melting ice-cream cones. It was a well-remembered ritual: licking your fingers and forearms, all the time juggling the cone, hastily upending it at the last possible moment before the cream plopped out as you reversed the inevitable drips from your elbow. There was a poignant awareness of leaving my childhood behind, of going on to bear my own child who would in turn enjoy the prodigal drippings of those lush cones and all of the other rituals of summer.

Upon reaching the hospital, I waddled in and stood in front of the receptionist while my mother parked the car. It was some time before she interrupted her phone conversation long enough to say, "Lab test? Downstairs," right over my query for the admitting office. Finding a quaint little elevator, I propelled myself upstairs, directly to the labor rooms. If the attendant was surprised, she was also efficient. She took my medical history and insurance information while I disrobed and provided her with a urine specimen. Then she took me to the labor room and put my legs high and wide into stirrups and sheathed them with coarse, white leggings. "The waters are about to burst," she exclaimed with genuine enthusiasm. "You can just start to push now. Push as hard as you can." She was a friendly, open young woman and put me at ease with her constant progress reports. Privately I thought of her as a cheerleader. "You're doing beautifully. Just fine. You're almost through the hardest part. Just one more push." Finally there was a minor explosion! I looked down to see her drenched. "They broke," she said simply, with an easy humor which lightened my bewildered embarrassment. She went to change her gown and then reported that she could now see the head. The excitement and intimacy she exuded belied the fact that this happens every day.

"Oh, good!" I exclaimed with great excitement.

She placed a mirror so that I could see the progress, too. I was temporarily taken aback by the very tiny spot of matted black hair which she so optimistically called "the head." Already the pain was excruciating, and I had to remember that every push brought Jeff that much closer to my arms. The progress seemed imperceptible, however, and always there was that screaming, tearing pain so different from the tremendous contractions. The dark patch of hair seemed no bigger than twenty minutes ago. After a while she left me, and from time to time someone in the hall would say, "We've got a natural going in there," and a head would pop in to offer encouragement.

Somewhere nearby a woman moaned and groaned in the most piteous fashion. Once in a while she would scream. Just lately my grandmother had told me about her first delivery. Her own grandmother had been a midwife in the Glenville hills for many years and was attending her. Grandma had started labor in the late afternoon, and as afternoon wore into evening and evening into night, Grandmother's attendant began to drift off to sleep. "She was awfully tired and I felt sorry for her. Every now and again I'd let out with a blood-curdlin' yell to wake her up." Her tired old eyes twinkled impishly with the memory. "Next mornin' Herman says, 'Julie, I heard you screamin'! It must have been awful for you. I thought sure you'd die on me.' I told him then that it wasn't so bad. Mostly I was just affeered of being left alone."

I tried to persuade myself that the woman was really not in such agony, but rather did the natural, uninhibited thing. Still, it began to unnerve me. When my attendant came in, I asked her if they could not give the woman something. She replied that she already had all they could give her. "She doesn't even know she's screaming," she offered. Somehow this knowledge distressed me further. Imagine attendants lifting your physical body, trying to move you while you know nothing about it! It seemed degrading. They were trying to make her walk, and their own groans punctuated hers as they lifted, hauled, pulled, and implored her to put one foot in front of the other. I felt a humiliating invasion of personal privacy, and I wanted none of it. This room, these leggings, stirrups, and loneliness were enough. One thing was certain, I must stick it out—if not for the joy, at least to avoid the utter humiliation I imputed to that unconscious, uncooperative state.

Fifteen minutes later I was questioning the doctor about just "a little something" for the pain, saying it was getting to be too much. He, too, assured me that I had been through the hardest part and was doing beautifully. Finally he announced that he had his fingers around the baby's head. "Just one more and we've got it! Push hard," he urged. I pushed and strained with all my might. I felt a sharp sting and saw the blood from where I had torn trickle over the baby's head. Instinctively, I paused for a deep breath. "Don't breathe. Push." he demanded excitedly. "Keep pushing. Don't let up. Don't let up. Push. Harder!"

The urgency in his voice frightened me. I pushed until my veins bulged and my head began to swim dizzily. Then I saw the head crown and the eyes and nose slip past—my baby's face—and then, *pop!* In that moment my baby's head was born. The wonder and exhilaration barely began to penetrate, as I gasped for breath. Only a couple of deep breaths were allowed, and I was urged to push again. With increased incentive, I pushed hard. As it began to look like we were in for the whole, long ordeal again, another explosion. Swoosh! The doctor caught the baby like a football. I was so surprised and relieved, I nearly laughed. The whole baby, there in his arms. Here in this room. "We have a boy," he announced. I was dizzy with excitement. I was glad it was over, and felt like taking Jeff to leave. The doctor, however, was working like a mad magician, cutting the tortuous, purple cord which swung in the air, and pouring blood from it into a lab tube. Everything was a blur of activity after an agonizingly slow pace.

The baby lay face up on my abdomen, covered with a yellowish film. The nurse used a syringe in his nose. "He's beautiful," I said, fully aware of my own prejudice and the considerable variance with what the world calls beauty. "What's the matter with his feet?"

"Oh, that's nothing. That can be fixed," the doctor answered.

The significance of this remark was lost on me. Later, when they took him out to clean him up and weigh him, I felt that they would return him promptly in a soft, blue blanket. I had shivered through the whole labor, and at times the attendants had worked without the air conditioner, sweating to oblige me. When they would sneak it on again, I would tolerate the iciness as long as possible before I told them how miserable I felt. I had genuinely appreciated their sacrifice, for it was easy to see they were uncomfortably warm, while inexplicably I was in the grip of cold chills.

We were still involved with the delivery of the afterbirth when Dr. Grace Jensen, the pretty obstetrician who ran the hospital, came in. She was alone.

"Did you know that the baby has a spot on his back?" she asked. Her voice was so unrevealing, so even, as to carry an ominous overtone.

"No," the doctor and I replied in unison.

"What kind of a spot?" I asked urgently.

"Just a spot. Nothing to worry about right now. I just wanted you to know." And she disappeared. Almost immediately after, my own doctor left, promising to find Carl and to bring him in. Only my cheerleader was left. "What did she mean?" I asked, searching her face. She busied herself briefly with some cleaning-up chores. She shook her head a little. She seemed as much at a loss for explanation as I. The silence screamed in my ears.

"A birthmark! It must be that. It could be that, couldn't it?" I rushed on to cover our awkwardness and my growing panic. "I mean, why would they call it a 'spot'? And anyway, what would I care about a little birthmark. Why would she come barging right in here to tell me about a birthmark. What would that hurt," I went on indignantly.

"It might be that. Try not to worry," she said gently. "Someone will talk to you real soon," she promised; and then she, too, was gone.

• • • •

When I looked up at Carl, I realized that his eyes were filled with tears, and he was unresponsive to the cheerful, excited greeting I had given him when he entered. I looked at Dr. Jackson and there were tears in his eyes too. Whether I could not face this, I do not know, but I began to ramble on and to try to share the excitement and surprise and miracle of Jeff's birth with Carl just as I had wanted to do.

"I suppose Dr. Jackson told you what a picnic we had," I said, looking from one to the other.

"Yes, yes, he did," Carl said slowly.

"You wouldn't believe it, you really wouldn't. It was just forever—his head—you'd never think it was so big. It takes such a long time. Not really, of course. It was just an hour. But it seems as if the hands of the clock don't move, and it's such a long time." Finally I relented. "Where is he? Did you get to see him yet? Isn't he wonderful!"

"Yes. I saw him," Carl replied. "Betty," he put in rather quickly, "there is something wrong with the baby."

I could not believe it, but there it was finally. No chance for joy—no time for wonder. How could they tell me this! It could not be true. I might have cried and clung to him to comfort his grief, at least. But I did not. I did not believe it. I knew differently. Our baby was all right. Hadn't we just gone through this extraordinary experience together? Hadn't I even watched Jeff briefly in the room as he snuffled around in the isolette, routing the blankets into as muddle and trying to raise himself on those sturdy little arms? He had managed to get up on his elbows before he flopped down and began crying indignantly.

I had no time to celebrate this child, to hold him, to behold his perfection, and they were asking me to share in mourning. There could not be anything wrong, and even if there were, he was our baby. We could take care of him. He was alive and well and strong. I knew that with all my heart. I could not share their pessimism.

Finally they took me downstairs and let me crawl into bed. The day was full of surprises. I felt as though the whole contents of my belly would spill out onto the bed with nothing to contain this catastrophe. After a while I got used to the feeling of having no muscle wall to prevent my internal organs from juggling around with every movement.

Finally when Carl appeared again, I could rivet most of my attention on what he was telling me about Jeff. He said that Jeff had an open spot on his spine and that it had to be closed to prevent infection. Dr. Jackson had assured Carl that we had a brilliant neurosurgeon right in town, and he personally had called him for us. The operation was scheduled for seven o'clock the next morning.

At last I began to grasp the seriousness of the situation. A baby, a newborn baby, not even a day old, being cut up. I could not believe it! Before I could comprehend it fully, Carl was defining another problem. Since the fluid would not be able to leak off from the opening in the spine anymore, it might build pressure in his head which could destroy his brain.

"Oh God! Why, Carl? Why? How could this have happened to our baby?" I cried in anguish.

Then, in turn, we would talk almost academically, trying to extend our understanding, trying to review the possibilities, trying to comfort each other, and trying by the very act of talking about it to forget that our own flesh-and-blood child was in such a tragic state. We mourned his condition even as we indulged our elation and joy at his birth. We were a mass of confusing and passionate emotions.

Finally Carl said he should get back to work and showed me the cigars he had bought. As I kissed him good-bye, I was filled with the greatest sadness. I was deeply touched by his pride. I felt, somehow, that I had let him down terribly, though I knew it was not my fault. I had not been able to present him with the perfect firstborn son. From the window I watched him cross the parking lot, his shoulders carried high and tight to his short neck. I could always pick him out of any crowd of men by those tight, square shoulders. I smiled, and tears stung my eyes.

I tried to be as cheerful as possible to my roommate. I felt apologetic for intruding on her joy, and yet I needed to talk. She was pleasant and told me about an excellent orthopedic doctor who, she vouched, worked wonders on her daughter's broken leg. I made a mental note. We would get him for Jeff.

The heat and humidity were unbearable. I was glad to be able to get up for the bathroom, but dreaded the awful stinging pain caused by torn tissue. My breasts, too, were painful and badly swollen even under my armpits. I had planned to nurse, but after Dr. Jensen had come in about the 'spot,' my obstetrician had said, "Give her the shot to dry her up." I had not questioned him, partly because I had absolute faith in his competence and judgment but also because, somehow, I knew he would not answer me. The contractions of my uterus were unpleasant, and, all in all, sore and bleeding, sweaty and aching, I felt "unclean"—more miserable than ever before in my life.

That night I was told I could see Jeff before they took him to City Hospital. The nurse wheeled him in and the neurosurgeon followed. I felt immediately cheered. More than anything I wanted to pick Jeff up and hold him, to reassure him and myself that everything would be all right. I leaned over him with happy expectation.

"Don't breathe on him, Mrs. Pieper."

I could not believe the reprimand from this handsome, brisk man. I looked at him with consternation. He introduced himself as Dr. Cooper. Of course, we had already talked about him and what he would do for our baby. I thanked him profusely for coming and expressed my concern for Jeff.

"He's a strong baby. He has a strong heart and there are no other significant defects. The meningomyelocele is one of the largest I've seen. I may have to graft some skin to cover it adequately," he went on in a brisk, businesslike way.

"Oh, God," I moaned. Was there no end to it? The doctor's self-confident, efficient manner seemed to instill me with courage and confidence, despite the dire possibilities he was revealing. He seemed to have an answer for every contingency.

"As I explained to your husband, after we close the spine and the cerebrospinal fluid cannot escape, there is a possibility of excess pressure building in his brain and causing hydrocephalus."

"Oh, Jeff. Poor Jeff," I murmured, leaning close to see his tiny little fingers clenched into the dearest small fists. "He is a fighter," I thought. "He can take it. You will be all right, Jeff, you will. If love can make you strong, you will be all right," I thought fiercely to myself.

"Don't breathe on him. Really, Mrs. Pieper, we have to exercise the utmost caution to prevent his contamination." Impatiently he beckoned a nurse to take Jeff away.

"Yes, oh yes," I acquiesced weakly. But it was too late. She had wheeled Jeff out.

After they were gone, I cried bitterly. I could not help it. I wished with all my heart that I could be home or in some private nook. There was nothing I could do for my own baby. I could not hold him, I could not nurse him, I could not even let him die—for the terrible infections would ravish his small body and the pressure might literally split his skull. Before today I could not have constructed such a terrible dilemma, and today it was ours.

Finally, I thought that perhaps they would need some skin for his graft. I wondered why no one came to me. Surely they could not take it from his small body. The additional trauma might kill him. The next best source must be his own mother. This gave me something to contemplate for a while. Perhaps, then, I could go to his hospital, to be near him. I mentioned something about it to a nurse. "Oh, I'm sure they have it all taken care of," she said. Much later I realized that her comment had given me no information on the procedure at all, and I lay awake all night wondering if I might not, in some way, be needed.

Another problem occupied my mind to a far greater extent, however. When I had asked Carl how the fluid from Jeff's back could hurt his brain, he had answered, "Well, as near as I can figure, it's a closed system, so the pressure will be the same everywhere along the line. It's a physical principle." It was all right for Carl. He was an engineer. As for me, I berated myself for my poor scientific background and agonized as to how in the world we could prevent the pressure from damaging his brain.

The only thing I could envision was a valve—a great, grotesque valve such as those on radiators. Suddenly, the idea seemed beautiful. Surely there could be some kind of a valve to control the pressure. Yes, the more I thought of it, the more I envisioned its possibilities. Of course, you could not just stick an ordinary valve, like a pressure cooker, on the outside of a child's head. Oh, God. What an awful state of affairs. "Dear God, what are we to do?" I prayed earnestly. I tried to calm myself and create a quiet place to receive His guidance. I thought of Carl, alone, too, at home. Surely, all of this was so wrong. There was nothing natural or at least nothing good about this experience.

I read my Bible, as I did each night. I searched it. I cried, I prayed. Something kept bothering me. The doctor had told us that the cord had been wrapped around Jeff's neck. That is why he demanded that I push even when I needed relief; that was why I had torn instead of being neatly cut and sutured. He said that almost certainly the baby would have been dead if I had had anesthesia. It was such a terrible thought. And yet, in the back of my mind I had to wonder, did God mean for him to be dead? Did my stubborn nonconformity bring this peril upon my child? And if, on the other hand, it is natural and good to bear your baby without anesthesia, then isn't it natural and right to simply pray that he will be well instead of delivering him up to a surgeon's knife. I had no answer for all these troublesome thoughts. Somehow I put great stock in the fact that Jeff was, after all, born alive. I thanked God and asked him to spare Jeff, to give us abundant strength and to show us a purpose, a God-pleasing purpsoe, for Jeff's condition.

At about eleven that night I had to realize that perhaps I had seen Jeff for the last time. I rang for the nurse and asked her to call our pastor and have him baptize Jeff. If she could not get him, then any Christian; but I wanted Jeff baptized. It seemed a very long time before she stuck her head in the door, and said, "It's been taken care of."

Perhaps I looked bewildered, because she added, "The matter you asked about."

"Oh, he's baptized?" I finally exclaimed.

"Yes," she said simply and continued her rounds.

Finally I could hear the distant roll of thunder. Heat lightning had been flashing across the sky all evening. I began to hope that a good, soaking rain might cool the oppressive air. I lifted myself on one elbow and then the other, trying to release the damp sheet which was firmly stuck to my body. After a time the rain began softly, and even in the darkness I could see the steam rising as in a teeming jungle. Lightning lit the room fitfully, and the thunder clapped sharply nearby, crashing among the trees which surrounded the lovely remodeled mansion that was the hospital. Only the faintest breeze moved the ghostly thin curtain now and then.

The violence of the storm was nowhere apparent in the room. My roommate shifted uncomfortably in her bed, wiping her brow and emitting a low sigh. Once she turned over almost angrily, trying I suppose, to get away from the nearly 100-degree heat. I thought of poor Jeff. To go through such a struggle to come into the world, and then to find it so full of thunderous rage and suffocating humidity. His poor nervous system, with a great hole in his very spine, must be shaken to its outmost limit; quite aside from being cut up early this same morning. What an awful welcome for a tiny, innocent baby. I just could not imagine why this had happened to him. I knew he would not even have anesthesia, just a little liquor, the doctor had told Carl. It would not help, I felt sure of that. The more I tried to leave Jeff to the providence of the Lord, the more I anguished at phantom contingencies and how we could meet them.

At last I returned to my Bible and the daily prayer guide. I opened to September 2, for it was now nearly dawn. The selection for the day was 2 Corinthians 12:9, "And he said unto me, 'My grace is sufficient for thee, for My strength is made perfect in weakness.' " Surely there were never three people each so alone, so vulnerable, so physically and spiritually weak, as our little family. It seemed as if God spoke across the centuries and through the night to our position and to us. "My grace is sufficient for thee." I grasped that promise to myself to believe we would survive this unholy day and prevail against whatever odds might await us.

Quite early during the morning, Jeff's pediatrician came in to introduce himself. Dr. Wexler was a short, dark man who spoke in a kind of tense, twangy voice. He explained basically what we had heard before. When he mentioned the pressure damaging Jeff's brain, I quickly asked about some kind of valve to control it. I was most anxious to have his opinion.

He seemed a little surprised and remarked that a valve was precisely the answer, and that one would be installed if the need arose. I was greatly relieved, but he seemed to regard me with a benign condescension. "You know, Mrs. Pieper, ten years ago these children could not be saved at all. This is a relatively new development. Many neurosurgeons still do not use it. You probably don't realize how fortunate you are to have these specialists right here."

"Yes. Yes, if it had to happen, we have a great deal to be thankful for. Carl mentioned that, too."

He had begun talking about the nature of brain injury, how little is known about it, how mysterious it is. "A child may learn to read and write and then, later, lose that ability. He might ride a bicycle and at age ten, for example, be unable to perform the same task."

When he left I was glad that, at last, someone had taken the time to talk to me, but I was not sure what he meant by all that he said. If the valve worked properly to control the pressure, which is what I agreed to be thankful for, why all this talk about brain injury? He presented a solution, praised it, and then went on to imply that we were, in fact, at the mercy of a bizarre curse and only awaited its fulfillment in whatever form it might lurk. Perhaps he was only trying to impress upon us the horrors of leaving our child without treatment. Or perhaps he was just enthused with the progress of his profession in alleviating human suffering. Still, it made me uneasy the way he mixed it up. Jeff might this, or he might that, or he might not even recognize you.

I went to weigh myself and, seeing that curiously I had not even lost Jeff's birth weight, decided to hope that those thirty extra pounds really did not show as much on me as they would on someone less tall.

The morning hung heavy with no baby to hold or feed, and watching all of the other newborns come and go. How I wished I were at home. One of my visitors that morning was the extraordinarily pretty woman doctor who owned the maternity hospital. Her eyes were the most vivid blue I had ever seen, excepting perhaps my grandfather's. Her blonde hair was cropped short to her head so that only a fringe framed her face. Even white teeth flashed with her easy and frequent smile.

"Right now the important thing is for you to get well, to take care of yourself, to recover completely. What happened to your baby is over. You must look out for yourself. You're still very young. You can have many other babies, good babies, perfect babies," she said, poking her finger at my abdomen.

"But Jeff," I began. I didn't want other babies. I wanted Jeff. I was miserably conscious of those brilliant, intelligent eyes boring into me.

"He has one of the most severe meningomyeloceles I've ever seen," she stated definitively. "He'll never be right. I know." She looked at me hard. My eyes were probably wide with wonder as I stared back at her, trying to understand what she was saying. "Look," she began in a slightly softer tone. "Yesterday he weighed 7 pounds, 2 ounces. Before I'd finished weighing him he had a bowel movement and lost an ounce. He'll not even have control of his bowels. He'll dribble constantly."

All of this did not make sense. Furthermore I did not see what I could do about it anyway. "But what can I do?" I asked stupified.

"Look, honey. I'm talking to you as a friend, not as a doctor. The doctors will try to talk you into all kinds of expensive surgery, and you can't afford it. And for what? He'll never be right. Just take him home and love him as he is, and have another baby as soon as possible."

I stared back in disbelief. Finally I managed to ask her something mundane about whether I should be up and about or rest in bed to recover the most quickly. She replied that lying flat or walking would drain my uterus best. I pulled myself out of the deep chair and walked her to the door, determined to leave this place as soon as possible.

The death the doctors had predicted for Jeff without surgery was not a pretty one. Yet there was no assurance that he would die without surgery, they had said; the hydrocephalus could arrest itself at any stage, and the child might live on as a helpless "vegetable," with the pressure stable and the brain damage irreversible, unable to even lift his own head. I could not believe Dr. Jensen was telling me to leave a human baby to those horrors just because he would never be "right"; she, who had every advantage money could buy or love could lavish, and who additionally was blessed with radiant, healthy good looks and intelligence. My mind boggled with strange and bewildering questions, for which there were only increasingly conflicting and incomprehensible answers.

That afternoon Carl's parents came. His mother, Florence, brought a gift. She gave me a perfunctory hug which reminded me of the obligatory gestures we were required as children to offer an embattled sibling, all the while pressing back hot, angry tears. Pop's eyes were openly reddened and he looked close to the husky sobs which had, perhaps, preceded. This was painful to see in a man unaccustomed to tears, a man who despite his years was robust and virile, who still split logs for his heat and shaved with a brush and straight razor at his outdoor sink from April to November. His stoic, even temper was almost maddening at times. When he spoke, his voice was a little unsteady and husky. He expressed his sorrow. So did Florence. They were in their sixties; this was their first living grandchild. They asked how such a thing could happen. I said that I did not know. No one seemed to know, I told them helplessly.

"We never had anything like this in our families before; not mine, not Florence's."

"We don't understand how a thing like this could happen." They seemed so American Gothic standing there—hardworking, expectant of blessings commensurate with the labor of their hands. I knew they could forgive the aberrations of nature when it involved hail, early frost, or high water. I knew that they were far less inclined to accept any imperfection in people. For example, it always seemed to me that their fierce loyalty to Carl hinged upon the fact that he could not be wrong—that in fact, they had to see him as perfect. I knew that when Carl's sister-in-law delivered her baby prematurely and the baby died, they had been heartbroken. Pop mentioned that he could not understand it, that she seemed like a good, sturdy girl of good stock. I knew that I had let them down, and even though it was not my fault, they would be looking at me through increasingly critical eyes. Even so, our mutual sorrow and their evident concern for Jeff would bind us.

"I know. Poor little Jeff. Why him? A poor, innocent baby." I could not even talk about it without crying.

When my own mother came bounding in, brightly painted and smelling beautiful, the heat and humidity were making me physically sick. I was depressed at having no word about Jeff's condition. "Hello, Butch. How you doin?" She called me by my East Side name, which had been coined in deference to my supposed toughness at the tender age of three, and had remained with me long after we moved from Forsythe Street in New York City.

"I'm O.K. I just wish I could get out of here to see Jeff. No one here knows anything about him" I complained.

"You need your rest. There's nothing you can do for him anyway. Bill told me he has the best of care." She referred to my obstetrician, for whom she worked parttime.

"I wonder if Carl has seen him yet?"

"I think Bill said he'd stop by after he mowed the lawn. He has some work around the house he has to get done. My God, it's hot in here. Don't they have a fan or something?" she asked rhetorically.

"I was just praying that it would at least cool off with that storm last night. It was weird, all that noise and hardly a breeze."

"It's that damn humidity. The storm did a lot of damage. Haven't you seen the paper?" I nodded, and she began to catalog the locations of various limbs that were down, much as she was accustomed to doing with other women's household furnishings, men's conversations, or the precise food she had dined on with her latest boyfriend. My mind began to wander farther and farther afield. My mother was telling how dejected and really bad Dr. Jackson, the obstetrician, had felt about Jeff.

Finally I interrupted. "Does Grandma know about Jeff? What did she say?" I asked.

"Oh, she feels bad about it. She's just praying for him."

"Poor Grandma," I said with genuine longing to see her. In many ways I was closer to her than to my mother. My mother and I never really conversed.

We talked mostly in parallel, and sometimes when I wanted to explain my interest in something, she would interrupt me to start chatting about someone or something else. My grandmother and I listened to each other.

The room was suffocating in its warmth. My mother was alluding to the discomfort in appropriate oaths again. "Oh God, I've got to get out of here. It's awful. I don't know how you stand it."

"I don't have much choice," I allowed.

"Stephen and I are going to the beach." Stephen was her boyfriend, a few months younger or older than I, I could not remember which. "I suppose everything will be mobbed today. It's the hottest day of the year. Broke a record." She tucked her hair up. "I've got to get going. Stephen's waiting. He didn't want to come up."

I was fervently grateful.

She bent down, and I kissed her good-bye. "Take care, Butch."

"Thanks for coming," I called as an afterthought, her heels already clicking down the hall. My mind was elsewhere.

The following morning, Dr. Jackson released me, not fully three days since I had walked in to deliver Jeff but far too long to be in a maternity hospital without a baby.

It was painful to see all the other mothers holding and cuddling, tenderly examining and feeding their babies, and never to have held mine. It was awful to walk through the halls like a homeless waif, fearing to intrude on someone's joy in the course of making small talk. I felt terrible to know that my baby was not in the nursery, to know that while the other husbands and grandparents clucked proudly through the nursery window, our baby lay alone and forsaken, probably in a haze of pain.

But these things went unspoken. The doctor did not want to hear how I felt when he asked how I was feeling. He questioned me from the door. I began to feel somehow set apart or unclean. It was painfully evident to me that even normally outgoing, sensitive people were discomforted by my grief, and, perhaps predictably, they expressed this by avoidance when the single most healing balm would have been communication. All of the unimportant things—to wear my girdle, not to climb stairs, to rest—all of the things I could read in a book, were addressed abundantly. But to gain real data regarding my baby's condition, to talk about my feelings and needs, to be alone with my baby and with Carl, those were not the fare of hospitals.

Chapter Two

Medical

When Carl and I reached the pediatrics wing, a nurse met us in the hall. She was a stout, cheerful little lady with warm brown eyes. "You don't have to tell me. You're the Piepers," she remarked with some humor. I must have shot her a completely stunned look, for she answered, "Jeffrey looks just like his daddy." We scurried down the hall, just as proud, elated, and relieved as possible. It was wonderful. She called him by his name and thought he was already a special person instead of "the baby" that all kinds of terrible things might befall, and little the difference. Someone told us to don some faded yellow gowns before entering the nursery to prevent contamination. We put our arms into the rumpled robes and tied them for each other in back with small, twisted ties. Then Carl, who had already visited Jeff, led the way to the crib.

He was just as sweet as I had remembered. His back was covered with bandages nearly up to his shoulders. He was sleeping fitfully. His ears were small and flat. His nose was sloped gently to a little button. I knew, even though they were closed, that his eyes were blue. Fine, light brown hair fuzzed his head, and in the back there was a distinct little ledge above the neck precisely like Carl's. "Oh, Carl, he has a ledge head just like yours. That's why the nurse thought he looked like you!"

"Thanks," he returned good-naturedly. "Next you'll be calling him a 'no-neck monster!' "

We watched his tiny fingers curl and tighten into little fists when he fussed. In between he seemed to sleep peacefully with the long, slender fingers only lightly curled. He was beautiful, and it was such a blessing to see him able to sleep in comfort. When he awoke, I noticed that one side of his face, near his eye, seemed stiff. When I realized that the right side of his mouth was slightly affected, I asked the nurse if it was paralyzed.

"He's had trouble learning to suck," she suggested, "but he's got the knack of it now. You should see what that little piggie took down this morning."

I liked her easy, open manner. We talked a little more as she went about her chores. "He gave us an awful scare that first night, I can tell you. He turned blue a couple of times. We almost lost him, but he's doin' O.K. now, aren't ya, Jeff?" She squeezed one of his legs playfully.

It was such a relief to see Jeff, to share my own concern with a responsive human being, to be answered in open, truthful ways, and above all to realize that the people here cared for Jeff, too—and that, in fact, he had not been alone.

Each day I drove Carl to work and got through the long morning hours as best I could until it was time for visiting, which ran from one until seven in the evening. There was always more than enough to do at home, but I could not seem to absorb myself in chores when I wanted to be with Jeff.

We had purchased the house in the spring, and it was largely unfinished. It was, essentially, a two-bedroom house built into the hill. From the yard there was a fantastic view, breathtaking in its expanse, and from the kitchen window a view of our road, winding and curving down from us with some farmhouses, barns, and sundry sheds nestled near the bottom. A long wooded stretch separated us from those houses and those people. At night a dazzling array of light which represented Schenectady and its suburbs clustered between the darkness of our rural night and the darkness of the vast sky. Somehow we seemed to have the best of both worlds—a lovely country scene by day and a city panorama of simple sophistication, distant yet intimate, at night.

Inside, because of limited space, we had decided to finish off the basement level in order to make a third bedroom. From the beginning I felt badly about a basement bedroom for a future child, but Carl dismissed my thought, insisting that it would be just as comfortable as converted attic bedrooms or any other bedroom, for that matter. On the basement level at that end of the house there were above-ground windows far larger than those in the bedrooms of most ranch houses. Furthermore, with radiant heat sealed into the concrete floor, the dampness would not be a problem. In short, Carl maintained, it was only tradition that bedrooms should be up instead of down. I could not buy the idea a hundred percent, but I did love our particular spot on the hill, and wanted more than one child.

Outside, the driveway was cracking badly with some pretty hefty weeds poking through here and there. Carl was anxious to preserve it, and indicated that the sealer had to be put on in the heat of the day; maybe I could get to it, since the baby was in the hospital. It was very strenuous work to spread the tarlike emulsion out properly. Openly, I resented the money he had spent on it, which we could ill afford. Secretly, I resented Carl for expecting me to do such hard work. I had begun to feel that he did not value me in some important way. I wondered if it could be that I disappointed him with Jeff. I found myself very hurt that he had not sent me any flowers after Jeff was born. Finally I told him about my feelings because I could no longer persuade myself he had neither the time nor opportunity. After all, he had bought cigars. His only comment was that he could not be expected to know a custom like that. For him it was just that perhaps—a custom, not an expression of any spontaneous feeling.

I ached badly and knew I was seriously "overdoing." The black top sealer was only part of it. When Jeff was less than a week old, I went to substitute teach for two days, glad to have something to really occupy my mind and equally glad of the extra money; I was truly panicked by our financial condition. Unfortunately, my homeroom was at the top of an old three-story building. I was exhausted by the climb. Finally, in our own basement, I slipped in the water which was ever present from my leaky wringer washer. Carrying the heavy, wet laundry up the stairs further increased the pain until I hated to move. I hobbled around, feeling like a split chicken.

If I felt like a chicken, Jeff looked like one. The first day his bandages were off, I found him baking under a regular incandescent light with the wiry black stitches curving low across the base of his spine and upward along one side, branching out to a Y and then one further branch. This, I could understand, was how the neurosurgeon freed up good skin, pulling it down this way and that until he could cover the lesion without a skin graft. With his little legs tucked up under him, Jeff looked like a plucked and skewered fowl. He was a sad sight, and obviously felt pain, judging by his fitful behavior. Sometimes we could recognize his bleating little cry from down the hall. I called him "little lamb." He also had a good, lusty, distinctly angry cry on occasion, which had such well-timed expression as to provide everyone with a few good laughs. He had a real personality already, and I could not wait to take him home.

Everyone commented on how well he could raise himself up so early. His head was steady and he almost did push-ups, fully extending his little arms. Even when he rested, distinct little biceps were evident. His legs were plump and full, but his feet flipped up and outward. I fondled his toes, rubbed his cheeks, and held his hand with its tiny fingers clasping mine for hours on end. I talked to him softly, whispering the same endearments and assurances over and over endlessly, willing him to be strong and well.

From our window at home we watched the neighborhood children across the street jump up and down on the roof of their station wagon. My mother commented snidely upon their impropriety. "If Jeff could do that. I'd be only too happy to let him!" I said. She shot me a disbelieving look of outright disgust. I was determined to spoil him in some way to make up for this terrible beginning.

If this was an unrealistic view, it probably stemmed from the fact that I had little actual responsibility for his care, so the whole experience was unreal in many ways. At night I would wake and not believe what had happened, in the way one wakes uncomprehending in a strange place. By the time my feet felt the cotton throw rug, I knew it was true, but it was not real. Jeff's room, with its stacked diapers and carefully cleaned and polished secondhand furniture only reaffirmed the lingering apprehension that I did not really have a baby at all.

One day, when Jeff was about a week old, Carl and I saw Dr. Callahan in the hall hastening along. I confirmed his identity with Carl just as he passed us. He was, we thought, one of the three neurosurgeons caring for Jeff. I turned back and hailed him.

"You're Dr. Callahan, aren't you?" He nodded almost imperceptibly and seemed perhaps a little annoyed at this interruption.

"We're Jeff's parents—Jeff Pieper," I added a little more tentatively. He gave no further sign of recognition or interest. "How—how is Jeff doing?" I asked, finishing quickly to cover my embarrassment.

"I've just seen him now," he responded, completely deadpan.

"Oh, good," I interjected at this sign that we did not have the wrong doctor.

"The kid's got meningitis, you know."

I did not hear the subsequent words trail off as he continued a brisk pace down the hall. Instinctively, I reached out my hand to touch the cold, bumpy wall as if for support. I felt my stomach slide, and my head buzzed with the dizzy loss of equilibrium which I now attributed to riding the elevator so much. A weak, sick feeling had been assailing me on and off, day and night, lately. At night it took the form of waves washing over me and receding. "Oh no, oh no," was all I could say, running my fingers up the wall in short strokes as if to smooth it into place. "It sounds terrible, I mean, that's like—I don't even know what it really means," I said in confusion.

"I was going to ask him," Carl put in defensively. "Only I thought you knew what it was." I wheeled around, but Dr. Callahan had already turned the corner and was out of sight.

"The kid"; it stung my mind. A tiny, newborn baby. "The kid."

Back in the nursery, the nurse said the meningitis could have come from a needle or something. Apparently Carl had signed for a ventricular tap which involved inserting a needle through the scalp into a ventricle of Jeff's brain to measure the amount of pressure building up, and to draw enough fluid off to relieve the pressure. We found ourselves largely guessing at all of these things and pumping the nurses for whatever information we could get to piece together as best we could. Sometimes they were very abrupt about terminating a conversation; other times they seemed willing to enlighten us to a considerable extend. Always they stressed how busy the doctors were, especially this famous, sought-after team of neurosurgeons, Drs. Cooper, Hayes, and Callahan. Always we were assured that we would be contacted about anything important. We were not even allowed to know Jeff's temperature or what medication he was on and why.

Except for signing forms and answering the constant questions about insurance, and making payments, we felt almost intruders in the care of our son. We did not really know whether he was expected to live or not. Dr. Cooper, our first neurosurgeon, seemed so confident and almost causual about fixing him up, while Dr. Callahan had seemed to convey a very different attitude, although neither of us could define it; impatience or annoyance, perhaps. With whom or for what reason we could not know.

There were almost no gifts and only a few cards of congratulations. It was as if Jeff never happened. We took one older woman home from church, and she said, "Wouldn't it be better for him if he'd die? Why do you want him to suffer so much?" Astounded, I managed to answer her by saying that we had to leave that to God. But in my heart I saw a healthy baby, and I wanted to believe the doctor, who after all knew a lot more about it than any of these well-meaning people.

One day Dr. Cooper called to say that Jeff needed the shunt surgery; the pressure in his head was building consistently. I was distressed, but he said we certainly did not want his head to become grossly enlarged and his brain irreversibly damaged. Without the surgery Jeff's head could actually split open, or he could live on unable to even lift it, unable to recognize his own parents; a virtual vegetable fit only for an institution. I asked if perhaps the pressure could ease off on its own, as I had heard. He was sure it would not at this time; they had already made studies to determine that. If it did at any subsequent time, the brain damage would still be irreversible if we did not do the surgery now.

He seemed piqued at my questions and assured me, they would not be asking this permission unless it was absolutely necessary. The permission slip was ready for our signature at the nursing station. He would appreciate our signing immediately. I assured him that we would. The surgery was scheduled for September 27. Jeff was not fully one month old. The monstrous cruelty of the whole situation weighed upon me and troubled my soul in a frightening way. Clearly we did not have any human choice, even if I could give up my stubborn, selfish desire to save this child.

Carl looked to the bright side. Once the surgery was over with and Jeff made it through, he would be O.K. When he was older he would have no memory of the pain. It was too bad, but not fatal. I realized how much I loved Carl, how much I relied upon him to help me keep a proper perspective and perhaps to keep my faith intact.

This time I looked forward to keeping the vigil for Jeff during his surgery. Carl pointed out that there would be nothing we could do for him, but it made me feel better to be readily handy instead of confined to a different hospital miles away, as I had been during Jeff's first surgery. I had, however, been bleeding myself ever since Jeff's birth and thought it was still my uterus draining. Even when I could not get up from the toilet and pull my napkin up in time to stop the brilliant blood from splotching the floor, I regarded it as only one more annoyance.

Likewise I was unable to step out of the shower without dripping thick, sweet-smelling liquid from my painfully engorged breasts. I went back for another shot to help dry me up, and the doctor allowed that it was "too bad" about Jeff because "you would have made a good mother." Out of politeness, I resisted the hurt, bitter temptation to tell him that that was still my hope. But it was a well-fixed prejudice—about nursing mothers being the good kind. In talking me into breast feeding he had emphasized cancer statistics so that if I would not agree for my baby, I would do so for myself.

The night before Jeff's surgery I hemorrhaged, passing clots as big as eggs. I guess I could have bled to death, as long as I had no large clots, and would have considered it only an annoyance. Finally I was frightened, weak, and sick. I called the doctor.

"How many napkins are you using a day." the nurse asked.

"About eight or ten," I said.

"A day?" she asked, amazed.

"Yes," I replied in embarrassment, abruptly realizing my stupidity. How was anyone to know, I thought defensively. It was a kind of cardinal sin to bother doctors unnecessarily. And very few took time to teach patients relevant medical information.

The doctor was on the phone. He asked me to meet him at Vista View as soon as possible. I asked why, protesting that I couldn't stay overnight because of Jeff's surgery in the morning. He reassured me that I would be glad to get the problem cleared up, that I would be out first thing in the morning.

"Have you eaten yet?"

"Yes," I said. "Why?"

"Well, it's O.K. Don't eat or drink anything else."

This time, in the same delivery room, I was given a shot that quickly made me dizzy, dry-mouthed, and thick-tongued. Instead of my friendly cheerleader of three weeks ago, I had the famous "Flossie." The women in our sewing circle hated her except one who maintained that she was only mean to sissies and bellyachers. She and Flossie had exchanged several dirty jokes. I needed no introduction; by her voice, her tough demeanor, her coarseness, I would have known Flossie anywhere.

"So you ate, huh? Well, good, maybe you'll choke to death," she said curtly in a soft German accent, which seemed incongruous.

"I didn't know," I began apologetically. Then I began to be frightened. I wanted to cry. "I could throw up—on purpose, couldn't I?" I said thickly.

"Forget it," she said disgustedly. She put a mask over my face. I began to sink down into a stupor. I was going to die, but I did not care. I saw the doctor smiling at my feet, and I heard Flossie already into one of her famous dirty stories in a mixture of German and English. I was happy to have the darkness cover me from the obscenity. From another world I now heard a rhythmic beep, beep, beep. Little yellow men—all nude, all in profile with their penises innocently dangling under the uniform curve of their bellies, were conveyed endlessly by. Beep, beep, beep, Kerpeep! One audaciously turned to face me before moving along in his preordained place. "Kerbeep, yourself," I heard myself say aloud with real anger.

In the morning I was clean, one light, delicate pink spot from complete purity. I left the hospital not knowing what the doctor could have done to perpetrate this miracle. Mysticism had prevailed over my timid questions. It seemed that I could never get a direct answer to anything. I began to be astounded by the way injunctions not to worry, little laughs, questions directed back to me or absolute silence replaced ordinary discourse in medical settings. Secretly I worried that I was sterile. Since there was no reason to think this and since my attempts at gaining information were futile, I decided to worry about it later. We left the hospital in high spirits to see Jeff.

My buoyant spirits were short-lived. Seeing Jeff was a shock. His ear was folded forward and taped to his cheek. A mass of thick gauze bandage covered the area from the top of his head to down behind his ear, and in his neck another bulky bandage. His head was shaved well back from the bandage, and his head, neck, and chest were covered with a gummy layer of orange antiseptic. The shock, of course, was his swollen, almost unrecognizable face, a pasty, translucent white. I held his hand, crying softly, in great mourning for his hurt.

A nurse came in, and answered my expression of concern with, "Well, it's a trauma to anyone's system. To have a hole drilled right through your skull."

"Oh, no!" I interrupted in my shock.

"Well, of course, Mrs. Pieper. They have to get the tube into the brain."

I looked at her with deep interest. She knew all these terrible and mysterious things that I did not. My attention was rapt. "Then he looks all right to you? I mean, considering what he's been through? He's supposed to look like this?" I watched her carefully.

"He's doing just fine. You've got a strong little fella there," she assured me. "I thought you knew that."

I turned to Jeff to hide the hot, bitter tears stinging behind my eyes. I bit my teeth hard together and felt the tense, prickling in my throat as I stared at Jeff. "Thank God, thank God," I thought. "It's all over. You'll be all right, my precious, precious boy."

Contrary to encouraging us to understand what was happening to our son and to gain the competent feelings which come from knowing how to affect and control one's life, we were discouraged at every turn. We were ignored with contemptuous silence, brushed off, threatened with withdrawal of treatment, and chided with everything from gentle condescension to open scorn when we tried to find out what was happening to our baby. Doctors failed to talk to us after surgeries where we waited, afraid to move, for five or six hours. Only a few weeks ago, more than fourteen years after Jeff's birth, the hospital librarian told me that I was not, as a parent, permitted to read the books and periodicals there. We learned to be ashamed of our legitimate concerns. With our questions and our mounting anxieties, we were left to trust the doctors to know and do what was best and to leave our lives, unquestioningly and with appropriate deference, in their hands. Sometimes those hands held incompetence and selfish interests rather than healing. What is unique to the medical world is that here, where one's very life and destiny are at stake, one has less recourse to social justice than in any other sphere.

By the time we took Jeff home, we had put bits and pieces of information together so that we understood that the shunt would take excess cerebral spinal fluid, which could cause increased pressure and expansion of the skull, from the ventricles of the brain and shunt it away into the jugular vein and then into the heart. Later, we learned it could also be drained into the abdominal or peritoneal cavity. One nurse told us that the system simply consisted of plastic tubing. When we saw a distinctly hard lump under Jeff's scalp, I arranged to meet the surgeon at the hospital for a quick check. His annoyance was ill-concealed. That was the steel valve which regulated the pressure. It was the first and last "stupid" question I remember asking, although I asked many questions in the days and years to come. Further, I wondered how in the world nurses and even ward helpers could pump the valve, which I was afraid to touch, in precisely the right spot if they did not understand the system better than they appeared to understand it. Perhaps Jeff paid a high price for that ignorance.

We first noticed his eyes roll down when we took flash pictures; so we stopped, and I contented myself by drawing charcoal sketches of him. Although the neurosurgeon said that I should not measure his head, I did and began to chart it. After Jeff had vomited a lumpy, violent stream four feet away, I called the neurosurgeons' office. Dr. Callahan took the call. He asked when our postoperative checkup would be, bade me mention this to Dr. Cooper when I saw him, and let them know if Jeff went into a coma before then. This was too much. I was beginning to understand the lack of bedside manner of this man; but a coma. Dear God. It was so frightening. What had we allowed Jeff to be cut up for if this was the shape of things regardless? Carl and I were utterly sick at heart. We began to feel we had been lied to, and that Jeff was being used in some experimental way. It was too terrible to countenance.

Before I left for the scheduled checkup I wrote three items on a scrap of paper: eyes rolling down, whites visible only; projectile vomiting; and head size 14¼ to 16⅜. We waited a long time, were ushered into a small cubicle, and waited again. When Dr. Cooper came, he admired his work on Jeff's back, pricked Jeff's thighs with a pin a few times, and dismissed us. I could not believe it. He had not regarded a word I said. As I flopped the last fold of Jeff's blanket into place, the paper wafted to the floor. As the doctor handed it back to me, he stopped short.

"Are you sure these figures are correct?"

"Yes. That's what I've been trying to tell you. You said not to measure, but I did, and it's happening anyway. Just what you said we'd save him from—a great big head."

Only then did he get Jeff's folder. Only then did he himself measure. Only then did he go for another graph and plot Jeff's measurements against the normal curve. Only then were we sent to the emergency room—more on the basis of a man's chivalry than his technical expertise. By the next morning, anyone could have made the diagnosis. The whole apparatus had slipped down into Jeff's neck, making a grotesque lump under the skin.

Only as the elevator swallowed up the tiny body strapped to the huge stretcher, taking Jeff to the operating room, did we realize the imperfections of the mechanical device and the technology upon which Jeff would depend for the rest of his life.

Our failure to obtain realistic data made our experience much worse than it had to be. Certainly there is a dashing of hopes and expectancies as professionals are quick to point out. But in our case, much of our anguish could have been relieved with honest, open communications. It seemed to me that professionals must understand that while it is true that parents are shocked and sometimes deny the child's condition, it is equally true that this is a sensible defense mechanism, especially in the light of the lack of real information they are given.

Likewise, many people, both professionals and lay people, cannot bear to look on a parent's pain. In this sense *they* are the ones to deny the situation. Sometimes they run away, either literally or by their retreat into silence, business, mock levity or unintelligible language. Often *they* are the ones who cannot cope. In their efforts to bring things under control and make things predictable, doctors may begin to treat parents as patients, to assign them stages for their psychological reactions and to insist upon passivity and trust.

Our dual needs to express our concerns openly and to be given medical data in a way we could understand were never met. This is not peculiar to the medical profession. Even though I was an A student in biology and life sciences, I did not connect vertebrae, neurons and dendrites to *people*. Even when I was finally told that Jeff's spinal defect could cause sensory-motor impairment, I could not process this information. As far as I could remember, I had never seen a person with a significant mobility impairment. I could not even remember seeing a picture of a person in a wheelchair. In my mind spinal columns in anatomy books had defects; what that meant in terms of people I did not know.

Likewise very few people seemed to realize that we needed to express our grief, shock, and anger. Instead of being encouraged to express our feelings and concerns, we were encouraged to quiet acquiesence, even when our anger was legitimately directed. Further, in our experience, simply expressing the same emotions over and over is little help toward real mental health. Information is needed to help people understand the mechanics of impairment. Feelings must be confronted honestly and head-on. There must be some recourse for legitimate grievance. Instead of retreating into their own sense of inadequacy, medical people should learn to reach out, if not with the arrogance of curing, then with the committment of caring.

It took nearly four years for us to realize that the care we were receiving was capricious and based more upon the value judgments of various men than upon even the prevailing and generally used technology. On one occasion, I insisted that Dr. Cooper see Jeff three times in one week. In utter frustration, he sent me to the pediatrician, who saw Jeff just hours before we admitted him as an emergency patient. Jeff's whole scalp was spongy with the cerebral spinal fluid leaking out from the burr hole and under his skin. The pediatrician had said, "He doesn't look so bad to me, Mrs. Pieper. You have to remember that we are not dealing with a normal child." Neither would acknowledge the complete change I showed them. Neither of them would use the ophthalmoscope at the end of their arms. Yet when Jeff was admitted by a colleague, he explained that Jeff's retinas were ready to burst. "Oh God," he whispered, shaking his head. "There is no reason for this."

Before we sought care elsewhere, Jeff was to be subjected to every indignity imaginable, even down to the stitches festering in his arm nearly a week after the other stitches had been removed—because it was no one's job to take them out. So they tore into Jeff's flesh day after day until I demanded the scissors myself, and someone finally made time to remove them.

One of the larger indignities was that Jeff's eyes remained permanently crossed after the second surgery, even though the pressure was brought under control. This meant that in addition to the neurosurgeon, and the pediatrician, and the orthopedic doctor, we now had to see an ophthalmologist on a regular basis. Dr. Biagi treated Jeff to a lollipop to gain his cooperation and called his nurse in to see a five-month-old baby relish the treat. It was one of the few times Jeff was treated like a valuable, real-life child. The doctor called him by his name, played with him, examined him carefully, and enjoyed Jeff for himself. He prescribed a patch to be worn on alternate days, first on one eye, then on the other. It was hoped that this would develop Jeff's vision equally in both eyes by forcing each to work for a sustained period of time, rather than allowing his mind to "look through" whichever seemed most convenient and less trouble to move.

In contrast to the respect with which we were treated by this man was the rancor displayed by the orthopedic doctor when I asked him to fill out some forms so that we might apply for state aid. This was unheard of, he declared, since we had good insurance. That was true, but we found it almost impossible to catch up on our expenses. Our share alone was already hundreds of dollars; the x-rays, specially fitted pillow splints, various homemade equipment, and endless running to doctors seemed more than we could manage. The spector of more surgery hung over us till I felt sick. I was surprised and hurt at the vehemence of his answer.

"What I can't understand is why you let Dr. Cooper go ahead with more expensive procedures, and then ask me for state aid."

I felt he misunderstood. "That is why, exactly. It's been so expensive already, and now we realize it is just beginning. We had no idea what we were getting into." There was an angry silence. I wanted to cry. "It's not that we don't want to pay for Jeff," I said defensively. "It's just that we have no savings, and even 25 and 50 percent is a lot with such big bills. If we could just consolidate so that we could pay a fair amount and know that we don't have to go bankrupt. That's why we're asking all of the doctors."

"Well, they won't do it. Not with insurance. It's too much red tape every time you want to do something. I won't work under the token fees on the state schedule."

He was really angry. He went into the fact that if I were not using private physicians I would have to take Jeff to the clinic and have everyone look at him like he was some kind of a freak. How would I like that? He would not even work at the clinic except it was expected of him. Finally he said that if we really could not afford it, he would take just the insurance for now.

"No, that wouldn't be right either. We really do want you to get paid," I said, not willing to talk because of the confusion and tears I felt welling up. "We understood that state aid is meant for exactly this kind of thing."

"State aid," he spat derisively. "Where do you suppose it comes from?"

"From taxes," I said without hesitation.

"Yes," he agreed snidely. "From my tax money."

I felt that I must confront the state with a failure of policy. What was one to do if doctors flatly refused to work under token fees? The answer that was given to me was that many doctors are willing, since they approve procedures every day under the program. We would simply have to find one who was willing. I thought that a very poor boat to leave an innocent child in, and it has not changed to this day. I had no desire to try doctor shopping on my own, and I did not want to see any other family in that bind either. Later, even without the spectre of token fees entering the picture, I found out how difficult it was to switch within the medical establishment. I was appalled at the arrogance and unaccountability of these men; at the breach of democratic process involved.

As a teacher, for example, I spent lots of extra hours with children and parents who probably had contributed not one penny toward my salary. Our school was in a poor district. Many were on welfare; others barely eked out an existence. Some of the children, on the other hand, were from small families in highly assessed houses. It never crossed my mind that this had any bearing upon how much help the child should receive either on my own time or during school. If I had any quarrel with the level of my salary or administrative policies, I felt it would have been my obligation to take this up with the appropriate people, not to take my frustrations out on the children or their families.

I could not understand why, even though they were not responsible to the public, these men would not take up their grievances with state and county administrators and area legislators, instead of practicing their own private vendettas, knowing that the parents had no democractic inroads. Many times I had felt how inadequate parents' recourse is even through their duly elected school boards, and how slowly change comes about. But at least there is a right to vote for representatives, speak out at public meetings, and even run for a seat on the board if people are not satisfied. Education, while an important area of a child's welfare, was no more important, certainly, than the nature of medical care available. Parents obviously had no democratic inroad, whether the fee was paid privately or out of tax monies, to assure that their children received quality medical care, or any care at all, at any price. It astounded me then, as it does today.

Many doctors who have the skill or expertise a child needs refuse to work under government fees. This is a major problem, but there are other problems. The financial means test dehumanizes some families, while others using the same test circumvent the spirit of the law with what amounts to regular abuse. Additionally, it is my understanding that once treatment is undertaken, the state and county need not become liable. That is, all procedures have to be predicted and approved in advance so that the counties can better estimate their budgets. This is particularly cruel when a family needs emergency care, as many children with spina bifida* and hydrocephalus do. Probably the cruelest aspect of all is the sheer inadequacy of the monies available. Many administrators will admit quite readily that one or two open-heart surgeries could wipe out the whole fund for the year. That means, quite simply, that many children cannot receive the care they need to avoid lives of enormous disability and confinement. It is a national disgrace that we would rather subsidize pseudomedical facilities for custodial care than to habilitate children at far less expense so that they can get around in their own communities.

More than that, it is a shame to us as a country that while there is no remotely valid check on physicians' incomes, families in need of help are regarded as ne'er-do-wells and subjected to dehumanizing financial scrutiny. A system built upon artificial scarcity of service necessitates that only some receive help. And it guarantees that people must feel apologetic for their need, and therefore for their very existence.

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*Spina bifida is the commonly used term for a split in the spinal column, which may be covered with skin and unknown (occult) or, which in its most severe form, meningomyleocele, involves the nerves of the spinal column as in Jeff's case.

Chapter Three

Family and Friends

My own optimism about Jeff's surgery was not universal, I soon found. On a visit to the Piepers' camp. Florence hugged me as usual. Carl went to seek out his father to say hello prior to going fishing, as was his habit. Florence pulled me aside, still in the kitchen, which was very unlike her.

"Who signed for the operation?" she asked in an even, urgent tone. Though she is nearly a foot shorter than I, I regarded her with intense bewilderment.

"Which operation?" I inquired, stupidly.

"The one to save him," she said resolutely.

I was beginning to feel uneasy and more confused. "Well, I guess I did. No, maybe Carl did." I was not even sure which operation saved him. I saw her face almost cruel before me. Her brown eyes, with their curiously downturned lashes, seemed to bore into me from under their menacing shield. "I--I honestly don't know," I managed. I felt dreadfully threatened by this little woman. "I don't see what difference it makes," I went on in the most steady voice I could. "We both want whatever is best for him."

She stared at me, not saying a word, hatred blazing from her eyes.

"I'll ask Carl," I offered, truly threatened. I backed toward the screen door. "Carl," I called, to no avail. I tried frantically to think what it all meant, what I should do.

Finally she spoke. "You have burdened my son for life," she said evenly, and turned her back to me and walked away.

Though I had fair warning of Florence's feelings by now, nothing could have prepared me for what followed a few days later. I had fallen into the habit of sleeping until after Carl had left for work. One morning I woke, thinking I had heard a knock. Knowing that my neighbor, Joyce, would open the door and call out, I figured it for a dream or the wind and rolled over. Still, it was stupid to sleep one's life away, to give in to depression. I got up. Outside the bathroom window, in our ragged backyard surrounded by the woods on three sides, a very kempt lady with two poodles in brace strolled as down Park Avenue. The sight was so ludicrous, both in its unexpected nature and in its context, as to remind me of Brigadoon and leprechauns. Seeing no car heightened my feelings of unreality. By now the bizarre and unreal were more commonplace than the real. I opened the door and called into the mist.

"Hello. I'm sorry I didn't hear you."

The woman turned and strolled toward me as if this happens every day. Finally I realized with embarrassment that she was a friend of the Piepers. She smiled and, to my great appreciation, introduced herself. Of course, she was a member of the Piepers' German sewing circle. These were people who came to this country at approximately the same time, had known each other intimately for years, and served as relatives to each other. Together they experienced all the ups and downs and occasional in-fighting which often accompanies sustained living together. I stood there in my shabby housecoat, pulling the ties tightly over my thick waistline, conscious that my face needed washing, that my acne lotion would improve my appearance if not the state of my skin. I was also conscious of the fact that Carl had dated the woman's attractive daughter.

I invited her into our scantily furnished living-dining room and went into the kitchen to fix coffee. We had a nice chat, considering my discomfiture, and I explained to her as much as I knew about Jeff, since that seemed to be her major interest. Her daughter was a nurse. Every now and then she would interject "Nancy says" this, and "Nancy says" that. I was hungry to hear any assessments, even secondhand, from an "authority," since information was so jealously guarded at the hospital.

Mrs. Mathers dressed with more style and seemed more contemporary than the other members of the sewing circle. Despite my unkempt appearance, I began to feel at ease. She seemed to understand the situation and what we were trying to do for Jeff.

At one point she leaned close to me, confidentially. "Tell me," she said, "is it true that it happened because of your bad blood?"

I was utterly stunned.

"What?" I asked unbelievingly.

"You know, your skin, dear. I mean, I know it's not your fault," she said gently. "It isn't as if it's your fault, of course," she reiterated. "But Florence said, you know, that it's because of your skin."

Through the years, I was to suffer various cruel hurts. Every time a new theory emerged on the cause of spina bifida, someone would call to inquire if I'd eaten any blighted potatoes or taken thalidomide. We were subjected to the grim suspicions of people, sometimes through the unthinking zeal of agencies to prevent birth defects. Friend and foe alike regarded us as suspicious organisms, and our lives became public property.

If, at times, it seemed that Jeff would never come home, and that crumpled hospital gowns and dreary eight o'clock suppers were a way of life, we were eventually informed that it was about to change. Jeff was to be released! October 13, a month and a half after his birth. It seemed so much longer, for we had been initiated into a bizarre world which, though it coexists with the regular world, is totally alien. We found ourselves alone in our exotic schedule and our inability to communicate our schizophrenic existence. The lack of comprehension of others combined to give our experience a nightmarish quality. Our sense of alienation drove Carl and me closer than before, but I was conscious of an ever-widening gap with others.

When people do not have real data, they invent fantasies to fill the void. I even heard suspicions that I had "done something" to my baby. These ugly imaginings extended even to my grandmother, to whom I was perhaps closest. Florence had been talking to her too. However, I realized that these suspicions lurked within many people, and that I would be burdened to outlive them.

In turn, I found a new anxious, even suspicious side to myself. I became neurotic about washing my hands and donning my hospital gown—only the latter being hospital regulations. After the meningitis, every time I suspected that Jeff's temperature was up, I eyed the nurses with apprehension. They not only failed to don hospital gowns but also wore their white uniforms on the streets, in their cars, in the rest rooms, and in the cafeteria. "How come only the parents have to wear robes? Just because they wear white, does that mean they are cleaner than we are?" I snapped at Carl.

When Florence came to visit Jeff, she held him fiercely close, to the point of excluding me. In a way, I could understand her anger at me, and I was thankful that she would not take it out on Jeff. When she was ready to leave, she put him down and instructed me that I was to leave him alone; he was ready to sleep. Before they were out of the yard, I had picked him up again, glad that she had "accepted" him and angered that she usurped him. When I noticed a deep mark on Jeff, almost directly over his shunt, I went to pieces. Before their car was out of the driveway, I wanted to call them back to discern what had happened. Was she trying to kill Jeff? Carl was his usual calm, unflappable self. I was ready to kill him, along with his mother. Finally, Carl came to me and asked if his mother had not been wearing a broach pin on her dress. Yes, that was it, certainly. And to this day, we do not know if that contributed to Jeff's first problem with his disconnected shunt. Certainly the stress of the whole situation predisposed me to return the ugly suspicions people were projecting onto me.

All of Florence's cruelties were unconscious, and one did not have to look far for the intention behind some of them. On a couple of occasions she angered me by saying, "You don't know what this had done to us. This is harder on us than it is on you. You wouldn't believe that, but it is true." I could not see why. They gave us no money, and they only baby-sat on two or three occasions. Each time Florence blatantly disregarded my wishes in regards to feeding Jeff, and twice she had caused him to vomit violently. Once she insisted upon his drinking beef blood to give him strength.

I knew that many people had major trouble with her throughout the years, but they all seemed content to shrug her off as a well meaning nut. Carl had always insisted that you could not talk to her, that she mixed everything up. It got so that the air fairly crackled with tension between us; not only between her and me, but between Carl and me.

On Jeff's first birthday, she presented him with a package he could not open and then declared, "Well, that's the way it is. Just can't do anything, can you Jeffy boy?" When he refused to show any subsequent interest in her presentations, she huffed off impatiently, letting her hurt feelings be evident.

Sometimes she would get on a binge of "Kick your legs, Jeff. Kick your legs. Got to kick your legs or how can you do anything?" I felt she was incredibly, if unconsciously, cruel, and I had no idea how to deal with her. Carl would have no part in speaking up, or if he did it was with such gross hostility that an all-out separation occurred. Much of the family tension through the years has been because I feel that Carl and others underwrite Florence's irresponsibility by excusing it as well meant or unchangeable.

Carl's axiom was, if it is not "on purpose," then it does not count. To me, if the effect is hurting, the motivation is irrelevant. You have to deal with the issue. But I did not know any better than Carl how to challenge beloved authority without being destroyed in the process.

Our first visit, on the way home from the hospital, was to my grandparents' house. Grandpa, who tottled like a zealous marionette, hastened to see Jeff. He had not been outside of his yard for years except to trim the grass along the sidewalk and curb with dogged regularity.

Grandma was an ample, not stout, woman with the swarthy, dark skin of a Hungarian gypsy to belie her German-Austrian heritage. She loved the outdoors and regarded the sun as healing. Every morning she pulled a wire brush swiftly through her waist-long hair, flipped and twirled and deftly secured a neat bun in place with old-fashioned hair pins. Her hair was still mostly black despite her seventy-odd years. The deep blue of her eyes was increasingly obscured by flecks of hazel. A bustling woman with large muscular arms and thick arthritic joints, she typically wore fragrant cotton dresses. Her dresses were starched in scalding liquid stirred with a wooden spoon and thickened in a large red and white enameled pan heated on the gas stove in her basement laundry room. The large room also served as a summer kitchen used regularly years ago on stifling days. I still remembered the table replete with cucumber salad and other warm, fresh vegetables from the garden. How on washday, the table supported the sweet-smelling starching operation. Those strong, competent hands reached into the scalding, milky half-jelled mass and deftly wrung one article after another into a long, twisted, writhing snake before it dropped into the wicker basket. The clothes lay coiled, fragrant, and comfortably faded, until the basket went up the stairs on Grandma's hip, its contents to be hung from the back window on the high pulley line which rode triumphantly out above the garden.

If Grandma, hanging fully halfway out of the window, was a source of concern, she was also a symphony of skillfully coordinated movements. Swiftly and deftly she snatched up a sheet, never touching the floor or window sill, arranged two corners together, plucked a clothespin from her mouth, and secured the corner. The sheet reeled dizzily out, secured in the middle for a graceful drape, and fastened at the last two corners to another article which had miraculously been shaken and readied for the faultless stroke which fastened it secure through the strongest wind. I watched fascinated while the items, first sheets and other white things, then light-colored prints, almost magically fastened themselves together, swinging farther and farther out, higher and higher over the garden, the basket emptying swiftly.

The years of sitting by, accompanying this homey activity with endless chitchat, the years of sitting silently next to my grandparents on the glider, rocking imperceptibly, the years of digging dandelions together with impersonal chastisement for an unwhole root being the only sound to cross the shimmering air, all these and the love and respect we bore each other greeted us at my grandparents' house. Grandma whisked off her apron and rubbed her hands together, brushing the flour from them. I gave over our precious bundle, and she took him into the spare room, delightedly babbling all the time. "Oh, you're home, little Jerry. Jerry Berry! You beautiful little fellow. Now you're home. Ain't nobody gonna hurt you no more. Your old Grandma's got you now."

I thought of the good smells of this house, of how whether it was the fresh-turned earth, the cool flowers or the warm vegetables, the starch, the snips of dough and pieces of hard apple dipped in cinnamon and sugar, or even the steaming smell of hot wool drying over the floor grate in the hallway—they were all precious to me. I hoped that they would continue forever, or at least so that Jeff could know Grandma and Grandpa and have those same memories.

Jeff was fussy. Grandma picked up a funny little chant. "Ah-uh, ah-uh, ah-uh, ah!" Every second syllable was accented with a little grunt and the last syllable was expelled with unequivocal authority as she bounced the bed to this primtive rhythm. Over and over, iamb after iamb, until Jeff fell silent. I wondered if I would know how to take care of Jeff. She began to unwrap him and examine him as I had seen the mothers in the hospital do. His little legs were already in full-length casts to correct his feet. She touched him gently with her fingers and then, as if assured he would not break, began smothering him with kisses and clucking endearments. A couple of times I reminded her as gently as possible that his name was Jeff, not Jerry, and so immediately she added this name to the rest.

At home our neighbor came over to share our pleasure in having Jeff with us, just as she had shared my joyous expectations at having a baby. (Her five-year-old had labor pains right along with me.) Similarly she had come in every day to hear the ups and downs of Jeff's struggle for his life and health.

While you can pick your world or your neighborhood to some extent, it is still rare good fortune to find a friend like Joyce Silva. She helped me to sort out reactions to all kinds of situations. She looks unfailingly at the best side of people; that is, she always asumes their motivations are impeccable and deals in issues, totally independent of motive. I learned to test my anxieties and my hopes against her good sense. If she thought Jeff needed help, she encouraged me to go back again or to try another way. If she felt that I was overanxious, she gave me her assessment and explained why she was thinking that way. If she saw that I was beat, she would comfort and encourage without judging my success or failure.

In short, if I would have the sense to learn in the easiest, most effective way possible—by observation, participation, and imprinting—Joyce is the perfect model. Nothing that is important to me has ever been discounted, but lots of trivia has been forgotten or modulated over a cup of tea or a glass of wine. By sharing Joyce's own ups and downs, I have seen effective ways of coping. Just as importantly, that makes me a friend instead of a client and helps me to feel good about myself.

When we became desperate for baby-sitters, Joyce suggested a girl up the road. Everything seemed fine, and our hopes shot up. Then, on every subsequent occasion, the girl refused with some excuse until I could not know if I was suspecting her unjustly or whether, in fact, I was slow in taking the hint. Finally Joyce explained that the girl's mother did not want Susan "taking the responsibility" in case anything might happen to Jeff. She was embarrassed to tell me, and I assured her that it was a great favor. Almost always a person can deal with situations best if he has all the appropriate data.

After that, Joyce enlisted her own son once, but we saw that he was so uneased that we did not ask him again. I was never sure whether or not this was because of Jeff's condition or simply the fact that he was not comfortable sitting with any young child at that particular time in his life. I do know that Scott is now grown and married and that his wife's only brother, like Jeff, has spina bifida. Scott is comfortable with Michael, and they are important to each other.

By the time we had invited a group of our friends over, Jeff was already sick again, and although they were congenial, perhaps their initial fears had been confirmed—that he was very different and very sick. At any rate, with the new bout of running to hospitals and doctors, there was little time to get together with former friends, most of whom lived in the suburbs on the other side of town and in an increasingly different world.

Jeff was not developing as quickly as most children In and of itself this did not bother us as much as the fact that we could not seem to get anyone else to take an interest in him, to treat him promptly, or help him to develop as much as he could. Quite to the contrary, other people seemed to discount the way we felt about Jeff and to almost ridicule the care and concern we lavished upon him.

Once when Jeff was hospitalized with acute pressure, I did not find him in his hospital room the next day. Instantly I thought of the mother who entered an empty room before the nursing staff could tell her that her son had died. I hurried down the hall, looking anxiously into every room, just barely aware of violating anyone's privacy. Finally, nothing was left except the nursery. He could not be there.

Again, I remembered his dire condition the night before. The pressure had him almost comotose, and the fluid was distending his scalp. As I peered into the nursery, I stopped dead in shock at the sight. A head, huge and grotesque, loomed from a crib. A head which nearly touched the bars on either side. A head pale and opaque, hairless and mapped with blue veins of every size running in every direction. I heard myself scream and tried to steady myself at the glass. "Oh Jeff, Jeff," I sobbed, even as I knew within the moment that it was not Jeff. A nurse appeared and I said, "I'm sorry, I'm sorry. I guess I thought it was Jeff." It did not matter. Nothing I had ever seen had made me feel such helpless outrage. I sobbed brokenheartedly. "It's awful. Why did this happen?"

The nurse smiled sadly and shrugged. There were tears in her eyes. "It is awful," she acknowledged. "The doctor told the mother nothing could be done, so she did nothing. Dr. Cooper was furious. We all are." Her voice softened as we approached the baby. "He's never had a convulsion, all these months. He would have been a smart little cookie." I could see a sweet face with its features small and undistorted, except for a high forehead and the eyes which rolled down as Jeff's had.

One ward helper, Ruthie, came in every day to hold Johnnie, often during her breaks if she was working elsewhere. It took two people to help her lift his head and arrange Ruthie and Johnnie in the rocker with pillows under the enormous head. Another woman, a registered nurse, took particular interest in Johnnie, too, wondering and fussing how she could get baby powder or some other "luxury" that state aid did not supply. Sometimes I knew they put it on our bill or on someone else's with insurance. Such was the manner in which people are reduced to small and large dishonesties in trying to love and care for children in the present scheme of things.

One day Johnnie's mother came. She wagged toys at him and toured the room, chatting with the other mothers. When I first saw Johnnie I knew that a doctor did not have the right to withhold information or treatment from a child. Then I was sure that a parent did not have that right either. And yet, I had a great deal of sympathy for Johnnie's mother and for her situation. I did not believe that a moral choice should cost as dearly as often was the case. She asked me a lot about Jeff and surprised me by saying that a surgeon had offered to do the surgery on Johnnie.

"What for?" she asked rhetorically. "He'd never be right. I mean your boy may turn out different. But ours couldn't be right."

She knew full well that Jeff wasn't "right." He could not stand or bear his own weight. He could not walk. He said only a few words. There was no way I could justify his existence by his achievements. All I could say was that I felt as if I would die of grief to lose him.

"That's because you have no other children," she replied. "I have a beautiful three-year-old girl who is normal."

I was shocked at this attitude and did not know what to say. In a few minutes she left, and was never seen again. When it came time for Johnnie to die, he was wheeled behind a screen in a darkened, empty room. Outside the door the nurse sat, her body tight with angry tears, folding diapers.

Almost every time we took Jeff into the hospital some nurse would ask if I had other children and reply that I really should. It was not fair to wrap myself up so in this one. I understood that having other children could be a tremendous incentive to going on, to absorbing oneself in the world again when a child died. But did that mean that you should love one less, or be less anxious when, in fact, things were not being handled properly? Would the existence of other children excuse one from being available to a child in need? In fact, I wondered constantly how we could find both the time and the money to care for Jeff adequately if we indulged our deepening need for another child. How would we keep ourselves from living through a second child to fulfill all our hopes? When I felt rejected by Jeff, abandoned by Carl, and worthless because I could not do the most basic, womanly thing right—produce a perfect baby—I felt an almost overpowering need to redeem myself: have a "normal" child. Was it O.K. to do that? Especially if it meant tempting oneself to give up the struggle for an existing child, to lay low and be quietly martyred?

If most people tempted me to quiet acceptance of medical and social neglect, Jacquie did not. Jacquie and I had known each other and had been fast, good friends for many years, since eighth grade. As a physical therapist, she took an even greater interest in Jeff than she might otherwise have taken. Although she lived several hours away, it was she who responded to my anxieties over Jeff's physical treatment and the moral throes of soul I had over situations like Johnnie. From the beginning Jacquie treated Jeff with respect, regarded him with pleasure, and predicted great things for him. She could not get over why the doctors did not get him going in some therapy, prescribe some braces, and let Jeff take off.

For me, dealing on a day-to-day basis with what seemed like mountains of indifference and even malicious stubbornness, all of these expectations were a source of conflict. She insisted that we should have his eyes straightened surgically. The neurosurgeon agreed. This would have suited me fine, since I felt that to be "cockeyed," as one child in the church nursery called Jeff, did not help in his relations with other people. And I was tired of dragging a forty-pound child up two flights of stairs to the ophthalmologist every few months. On the other hand, I was not thrilled with the idea of giving Jeff over to his first optional surgery, perhaps threatening his life for cosmetic purposes. The ophthalmologist suggested that we wait till he was six, to give his vision a better chance to develop. Thus I immersed myself in reading and correspondence to understand whether or not Jeff's chances for binocular vision would be significantly improved with surgery, and whether or not that might increase his capacity to learn and interact with people and his environment in more positive ways.

Meantime, I continued to pressure Dr. Danforth, the orthopedist, to give Jeff some therapy or at least an evaluation. Finally, in sheer desperation, I just sat in the clinic and cried. I could not say thank you, smile, and leave another time. I could not move. So I sat, crying and feeling helpless and stupid. Before, I had always presented my arguments to the doctor rationally, if with animated frustration. In turn he had countered over and over that it was "economically unfeasible" to brace Jeff or "waste a therapist's time" on him; that even if they did get him walking, he would not know where he was going; and that even though he might make out all right physically, you "couldn't discount the brain damage." All of my anger at the arrogance of doctors and the perversions of human development, the unjust and unaccountable control of Jeff's fate, just spewed forth amidst tears of frustration.

"All we want is to see a therapist and let him decide if Jeff can walk. Is that so much to ask?" Perhaps the doctor perceived that this was not such a gross request. Or perhaps he realized I was not going to move. I was paralyzed with frustration and sodden with desperation.

He agreed to send us upstairs. The therapist, a friend of Jacquie's, as it turned out, wrapped Jeff's legs in *Life* magazine and stood him at the parallel bars.

"Now, let's see what you can do," he said amiably to Jeff.

"Do?" I thought with panic. "*What in heaven's* *name is he supposed to do?"* I was scared for the man to let go of Jeff, not because I was afraid that Jeff might fall, but rather because I perceived he might blow his only chance. I prayed desperately that I could discern what it was Jeff was supposed to do in time to give him some clue. The therapist let go. Jeff pitched forward crazily, caught himself, threw his chest out like Peter Pan crowing, and stood there as happy as I have ever seen any two-year-old anywhere. I was filled with joy for him and longed for Carl to be able to see the spectacle in its full glory. The therapist called down, left the message that Jeff was ready to ambulate, and we left completely enamored of the whole world—and especially of the therapist who had given up his lunch hour to evaluate Jeff.

It was a joy short-lived. By the time I had contained my patience about as long as possible, hoping for a speedy appointment, Jeff was hospitalized with a temperature of over 106 degrees. The experience was devastating. A lab technician stood at one arm trying to take blood, a nurse stood trying to get an intravenous needle into the other arm, and two people fiddled with the ice bucket and mattress at the end of the bed. The intern suggested that I might want to leave, and I declined, knowing that I could be of some small support to Jeff. When he announced that he was asking me to leave for my own good, I declined again, saying I felt better to stay. Finally, he threatened to put me out forcibly. This shocked and angered me. Rather than have Jeff endure such a spectacle, I left, crying almost hysterically. I fervently wished the intern would drop dead. To me he epitomized the whole medical profession at its worst.

Many times I had looked on while someone's nervousness caused Jeff additional pain. Many times I had forgiven outright incompetencies because of my silent sympathy for those who tried to help. But this day everything broke loose inside of me. That an intern's defensiveness should separate me from Jeff when we needed each other, upset me. That he could exercise his power without any just cause and without benefit to us and then pronounce this for our own good, enraged me.

As I listened to Jeff's screams before the elevator finally engulfed me, I felt physically sick. Once inside I pushed the button for the lobby and the only place in the massive hospital which afforded some privacy, a small toilet near the front desks.

I was so eternally sick of the unreasonable force, the invasion of privacy, the patronizing atitudes and wretched separations which had characterized our hospital experiences. I was particularly sick of the need of the medical establishment masquerading as the needs of the patients. I sat for a long time on the closed toilet lid in the little bathroom. It was probably the only humanized fixture left in the whole place. Around the corner a great sign on the library door proclaimed "Authorized Personnel Only" so that the esoteric knowledge or ignorance of the profession might be held close to its collective heart. Many years later I learned that there is probably not one piece of material in that library which is written by a consumer or which would allow medical personnel to understand that they are dealing with people who have the same needs for respect and fair treatment as they themselves.

I spent some of the worse moments in my life in that little room. I watched my hands and arms and knees shake uncontrollably. I did not know what was happening to me. I could not put names on the ways I had been treated. I only knew that I felt angry and humiliated; that I had screamed at authority and defied my gods; that I was body and mind, out of control and alone. Most of all, I needed Jeff as much as he needed me, and I knew that my behavior could separate me from him. If I went to pieces like this, I thought I might be thrown into the psychiatric ward.

I wondered if I was crazy. Was I the only one in the world who perceived it, why was nothing done? If only I perceived it or would fight it, did that make me crazy? It was a terrible experience for I realized that no matter what I did, whether I accepted the ways of the hospital or fought back, I would not feel good about myself.

We never heard one word of the results of the endless blood tests and urine specimens. The pediatrician never returned my calls. One day a bill arrived for $60 for six hospital visits by the pediatrician. The next day another envelope arrived from the same office. I had hoped it was Jeff's diagnosis, for without knowing the cause, I felt terrified that the malady would descend again out of the blue. But it was another bill for $15, reminding me that we had stopped at the doctor's office briefly before going on to the emergency room to be admitted.

The nurses were more close-mouthed than ever, except to say that the intern was testy and short-tempered with everyone; probably worried about impending exams. At the time I fervently hoped he would flunk. I felt that he was unfit to be a doctor. Through the years I have come to conclude that the nature of a physician's training breeds a good deal of defensive high-handedness which is quick to surface when an anxious doctor faces an anxious mother over a sick child.

Interestingly, I did not find out what ailed Jeff until the fever racked his small body a second time. This time I told the doctor that I did not want Jeff admitted to the hospital. I felt I could not go through that again even if Jeff could, and I wanted to test the doctor's reasons for wanting him there. Everything I had seen them do could be done as an outpatient or by me at home.

After Dr. Wexler had called me a very stubborn woman and allowed that he had expected to see Jeff dead long ago except for my good care, he exclaimed, "Well, I guess we'll have to presume it's the same thing as last time."

"And what is that?" I inquired.

"A urinary infection." I did not know why he suspected this. I was content that he would let me take care of Jeff at home.

Later, when I called the rehabilitation hospital, they could not find Jeff's records. Finally the office of medical records called back to report that they had been located in the inactive file. "Apparently," the woman replied to my rambling expectations of braces, therapy, and walking, "Dr. Danforth feels that there is no further need to see this child."

Feeling that my whole world had collapsed and that I could not endure any longer as a whole person, I made an appointment with a psychiatrist. He allowed that he or his wife would be as upset as I under the circumstances I had described. If what I was telling him was true, he said, the doctors were being unfair. He promised he would talk to them all, and act as a liason. I liked this idea very much because he promised that he would garner some solid medical information and interpret it for us.

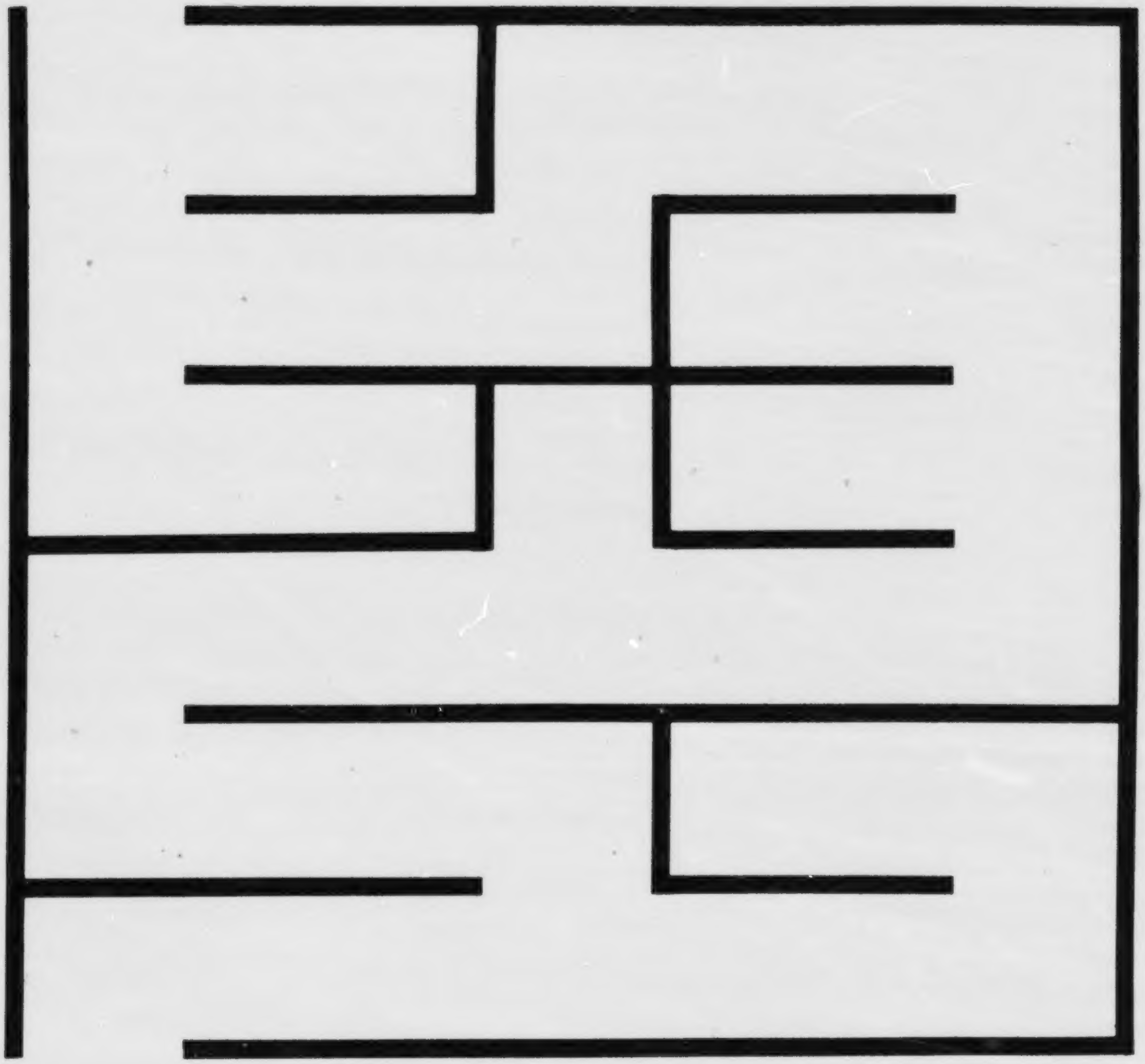
After many visits by both Carl and myself, I asked him about his promise. When he had talked to all of the people involved, he presented his conclusion to me alone: Jeff would most likely die of renal failure. After all, he had already suffered two terrible bouts with high fevers and urinary infection. He explained that Jeff's lack of voluntary control had implications medically as well as socially. His inability to void completely and at will would contribute to infection and eventual destruction of the urinary tract.

I was shocked and spent the whole hour crying, asking over and over what we could do. There was nothing; we were already doing everything possible for him. I was sick to think we had saved Jeff from one fate (infection and the "big head") only to let him die of another (infection and renal failure). There was no sense to what we had done, it seemed. After three and a half years of anguish and financial stress, our good intentions seemed an obscenity. What suffering lay ahead for Jeff I could not imagine.

My need for accurate information had led me to the psychiatrist. Ironically, although I suffered in believing his interpretation, the message that nothing could be done was more of the tyranny of ignorance which kept us from feeling adequate to master our fates. But we did not learn this until later.

Chapter Four

The Road to Philadelphia



The sense of betrayal by our doctors underlay even the shock and pain of possibly losing Jeff and being powerless to help him. I sank into the lowest despair of heart, knowing too that Jeff was having trouble with his shunt. Only a few weeks after the last surgery, Carl and I had borrowed a tent and took Jeff with us for the Fourth of July weekend. Though he loved the trees and the outdoors, he became wild and overly excited. He began to act so strangely that we pumped his valve, to find it collapsed instead of responsive. We dashed home to the doctor.

But, of course, the doctor was not at our beck and call, and when I went in for the appointment days later, he began the usual song and dance. It does work; it does not work; always concluding it worked sometimes, and that should be good enough. Besides he is not doing too well anyway.

Jeff had been whiny and irritable, his moods punctuated by episodes of wild excitement and uncontrollable laughter. I felt the shunt had not worked properly for months and that the situation was becoming more critical. I took him to the neurosurgeon again. Again I was told, it pumps now; now it doesn't. Well, it works some of the time. Let us know if something dire happens.

I prayed a lot. I thought a lot. I felt unable to challenge our doctors effectively. Finally I faced the fact that I did not trust them. I did not even trust their medical competence, although they were reported to be some of the best in the country and held positions of honor in the medical hierarchy. More particularly, I knew they did not value Jeff. Perhaps there was no way I could enlist their supposed expertise on his behalf. Thus, the possibility began to churn in the back of my mind that there might be some help for Jeff of which we were unable to avail ourselves because of the attitudes of these men.

Finally I called a young mother whom I had met in Dr. Cooper's office. Linda's child had looked anemic and far less aggressive or mobile than Jeff, even allowing for her younger age. I felt a little guilty to call because I thought that even with all of our problems Jeff might be doing lots better than Sally, and I did not want to hurt Linda. I knew too that Jeff's progress was so slight as to be a disappointment to her in her love and expectations for Sally. It was a dilemma. In the hospital, the doctors had warned about the "dangers" of parents talking together and refused to give me any names. I felt guilty to defy the authority which always purported to act in my behalf. Still, I sensed in Linda the same quiet terror that I was feeling, and I needed to know if she had found any answers for her grief.

Our conversation was extraordinary. She told me that Sally had indeed gotten so bad that she did not even know her own parents, that she was drifting into a coma. Although hospitalized, the doctors would do nothing for her. Her husband finally said, "If you can't or won't do anything for her, I'll find someone who can." They pulled Sally out on their own responsibility and took her to a neurosurgeon in Philadelphia, where her shunt was revised and she began talking in whole sentences, writing and reading words within weeks. I could not believe my ears. Finally, in the background I heard, "Are you going to get me the cookie, or not, Mommie?"

"'Who is that?" I asked in surprise.

"Oh, that's Sally. We have been on the phone such a long time and she's getting so impatient with me."

Linda informed me that it was just nonsense that nothing could be done about the urinary problems. Dr. Spitz, their neurosurgeon in Philadelphia, had referred them to a urologist down there and he took x-rays which were openly shared with them. Then he taught them how to "credé" Sally—that is, perform credé maneuver, which consists of emptying the bladder by manually pressing just above the pubic bone every three hours. This was meant to cut down on the chance of infection and prevent pressure from building and distending the bladder and ureters, which in turn could damage the kidneys. There was no shunt and valve for the bladder as there was for the fluid in the head, but it could still be emptied periodically so that it would not cause trouble. I was fascinated, and alive with new hope.

I wrote a letter to Dr. Spitz that very afternoon, describing our dilemma and begging his help. But before we could get down for the surprisingly early appointment Dr. Spitz suggested, Jeff's shunt fulfilled all of my suspicions by ceasing to work almost entirely. He would be hysterical with laughter and lose all sense of balance sitting, plunging forward self-destructively with shrieks of laughter. Characteristically, our neurosurgeon was ambiguous. He was only momentarily stunned when I showed him the bulge of fluid under the skin behind Jeff's ear which occurred when Jeff began screaming. But still, we would "wait and see."

Carl and I ended up in Pennsylvania with Jeff at 2:00 A.M., trying to find a hotel we could afford with the pittance we had left. After the six-hour trip by car, we were feeling exhausted and terrified at the thought of an expensive hospitalization so far away from home. The only thing that sustained us at all was that the alternative was unthinkable.

To make matters worse, Jeff grew critically ill after the surgery which Dr. Spitz performed a few days later. Each day I went in to find him more and more grotesquely swollen, until his face was unrecognizable. One eye formed a tight slit extending almost to his ear, and both eyes were black and blue. He was terribly congested. A machine stood by his bed. I suspected this was to pump out his lungs. Because of problems with the intravenous feeding, there was a local swelling in one arm or the other day after day. But I was told nothing. Once I noted that his temperature was 102 degrees before the nurse grabbed the chart and declared, "You know you're not allowed to read the chart." One nurse refused to tell me what medication he was on, saying, "I don't think parents should know when their children are on narcotics."

Another time a nurse stuffed food into Jeff as he lay gagging and vomiting flat on his back, spread-eagle and lashed to the crib bars by his ankles and wrists. In anguish, I begged her to stop, fearing he would aspirate food into his lungs. She swore curtly and told me to get out. I almost fled the ward. I felt an almost overpowering rage. I wanted to grab her and physically fling her away from my child, to brutalize her in the same way she had hurt Jeff. But I knew she was angry inside and was taking it out on Jeff. I did not dare to do anything to further provoke her. I went to the ladies' room and vomited violently. I was sick with self-hate and rage and above all, helplessness. Even many of the fathers were concerned for Jeff. But everyone admitted that you do not speak up to doctors, and you do not rat on the staff. They have access to your children. We were all sore afraid.

Finally after another shunt revision and the torments of hell, Carl came to retrieve me and Jeff, so that I could go home to have our second baby. I could not wait to be sure that everything was all right. Among other things, I had learned that my chances were considerably increased for having another baby with spina bifida, although all of our doctors had assured me it was random or "one in a million." I should not have been surprised that this was just one more area in which I was, wittingly or unwittingly, misinformed by those who generally controlled such information.

To our great happiness, Julie was born vigorous and without major anomoly. She craned her neck this way and that to stare out from her fierce-looking eyes, obviously unaware that she was not supposed to be able to see much. The bottoms of her feet looked more like palms than soles, and her toes moved more than her fingers, grasping and stretching like a monkey. Her face was very pushed in, with a flattened nose and a forehead which sloped almost to a point beneath the thick black hair that stuck out in every direction. Bright red birthmarks splotched her forehead and eyelids. I worried that she would be handicapped by her appearance, even as I felt gratitude for her good physical condition. One of our friends said she looked just like a German barmaid, and laughed. Everyone laughed at her because she "looked funny," and they laughed at me for my deep and serious concern.

After a couple of weeks I cut her hair off and took her to the dermatologist. Soon blonde curls began to fringe her face, the birthmarks faded, and she grew beautiful. But I had gained a new awareness of how much we value physical beauty. This has helped me to understand the stigma and disappointment parents and children with disfigurements experience and to appreciate how our culture encourages the sequestering of people who look or act different.

Jeff did not improve after surgery as we had hoped. After he came home, he talked more, named colors which we did not think he knew, and greeted Julie with a verbage the likes of which have never passed his lips before or since. He was comfortable and content for the most part, but we saw clearly that some of his achievements were markedly better than his overall performance. This filled us with guilt that he was not functioning at his capacity and increased our feelings that we ought to be doing something further to stimulate his mental development.

I searched every local alternative possible including Shriners and other orthopedists. In desperation, I tried the local rehabilitation clinic one more time. My malaise of soul probably rendered the car impotent, too, for it would not start. When I arrived almost an hour late, the head nurse informed me that the doctor had left. I did not believe this, since the clinic had the habit of scheduling everyone for nine o'clock, and I could not remember ever having seen the doctor before ten. I tried to press by her, sure that she was lying. In the hallway I would find the usual mass of people still waiting, I knew. She grabbed my arm and stated flatly, "I'm sorry, but you cannot see the doctor." Her smile was sweet, her voice was soft. She turned me around gently. "Besides, you go to Philadelphia now. We don't treat their patients," she continued, still smiling, her gray eyes filled with coldness.

"But we go there for his head. We had a terrible time here, you know," I trailed off defensively, looking at what seemed to me the rank hatred in her eyes. "We only go there for his shunt," I continued weakly. She stood solid, barring my way ostentatiously, a sardonic smile touching her lips. I felt frightened, confused, and angry. "There's something wrong with Jeff's hip, I think. I mean, it's a structural thing," I said, trying to explain. "It's bumped out on one side. It hasn't anything to do with neurosurgery. . . ."

"Mrs. Pieper," she said in a pseudo-sweet voice, "Why don't you go back to your doctors in Philadelphia and see what they say." Her eyes and something in her mouth expressed a malice which I could not comprehend.

Once again I found myself leaving the rehabilitation hospital in tears of frustration. Why did everyone treat me like some kind of a nut when all I wanted was their help? Not even for myself, but for a beautiful, innocent little boy who had never done anyone any harm and who already had a rough go of it.

We were a little leery of tying in with the type of therapy which many of Dr. Spitz's patients were on —the Doman Delacato patterning program. There seemed no doubt that it had helped many in ways hardly short of miracles. But it involved time and expense we did not think we could afford. We preferred the more traditional treatments for Jeff, but it was now evident that these were to be unavailable to us. On the next visit, nearly a year after Jeff's shunt trouble, we presented Dr. Spitz with the whole dilemma and asked his advice. Dr. Spitz did not believe in traditional therapy. His own daughter with spina bifida was on the Doman Delacato patterning program. He recommended it to us. We protested. "What are your alternatives?" he asked. There were none. So we made an appointment for the initial evaluations.

Chapter Five

Patterning

The appointment was to consist of a thorough physical examination, an evaluation of various areas of development such as auditory, visual, motor, tactile and language, as well as lectures on the theory, philosophy, and research relating to the program. Finally, an individualized program would be prescribed for Jeff. We would be at the clinic for two days, from early morning to late each night.

We stayed with friends, the Bernsteins, who had recently moved to the Philadelphia area. A record-breaking snowstorm closed even the Catholic churches on the Sunday morning of our 7:00 A.M. appointment. Karen vowed that we would never reach the clinic; and from the way she had seen people grabbing up bread in the market, she was sure we would be snowed in for days. "Honest, they don't have plows here," she kept repeating, as if trying to come to terms with her own disbelief as a transplanted upstate New Yorker. Not happy to contradict her good sense and new insight, I felt equally constrained to point out that anyone who would make appointments at 7:00 A.M. on a Sunday might just be fanatic enough to get there regardless of the storm. In deference to my anxiety, the Bernsteins enlisted their neighbor, Jack, who not only owned chains but remembered how to drive like a North Dakota native. Sure enough, we passed tiny plows here, there, and everywhere, many of them stuck themselves; but in the end Jack got us there. And sure enough, every parent who wanted to help his child, plus the full cadre of professionals, were waiting there.

The lectures continued into the night, with the children scattered asleep all over the floor on blankets, coats, and sleeping bags, with one of the regular staff baby-sitting. The theory of the program was that an infant's ordinary body movements stimulate brain development through sensory-motor input. Gradually the child's movements become coordinated in cross-pattern crawling, creeping, and walking. It was hoped that by stimulating the body in various ways we could "wake up" and condition the pathways to the brain and activate the millions of unused cells within the brain itself. The method involved artifically re-creating early developmental patterns of movement in hope of reaching the brain and having the brain take over these same movements on its own.

We worried because Jeff was one of the few children who had a spinal cord injury instead of simply damage to his brain. Everything told me that this had to make a tremendous difference, but we would not know until we tried.

We were to have no music in the house, not even a television commercial. Music was thought to interfere with the establishment of dominance in the brain. The theory held that a dominant hemisphere was the seat of language skills. It reminded me of the average person's attitude about the school budget: reading, writing, and arithmetic were primary, while music and art were frills to be sacrificed if necessary. Of course, there was no proof of any of this, but I wanted Jeff to be able to communicate in *some* way; music would be a small price to pay. Sometimes I just prayed that if he would be able to ask for his basic needs and to tell me when he was in pain or why he was angry, I would be satisfied.

Dr. Downing emphasized that crawling with the hands a certain distance from the eyes, out at each side alternately, was helpful in establishing hand-to-eye coordination and the ability to focus at the proper distance for reading and writing. He pointed out that in some cultures where the children are not allowed to crawl, either because of poisonous snakes or because their mothers value placid babies, it is hard to teach reading and writing at close range. In these same cultures, however, the people are often good hunters and can learn to read from a distant blackboard. I found this fascinating.

As Dr. Downing emphasized the positive effects of crawling upon vision and the brain, I was reminded that when Jeff pulled himself around, his little fists alternately crossed right under his nose. Suddenly I could believe that all of his crawling had reinforced his cross-eyedness. I expressed my concern to Carl. If I had to crawl around like that all the time with my fists coming across my line of vision, I thought that I would be cross-eyed too. I wondered if Jeff could learn to crawl with his hands open, the palm flat on the floor and his stroke well out in front and to the side. Carl did not think so. "He's strong, and if he does all the crawling they want him to, he'll get stronger. But I don't think he can ever do it the way they want without the use of his legs."

We left Philadelphia exhausted, with a great list of things to buy and to make and with a schedule that would be hard to fit into the standard day. We needed a coordinator to schedule volunteers and enough of these volunteer helpers to "pattern" Jeff four times a day. I was not optimistic about finding all of these people, for we did not have an active social life, and the few friends we did see were all terribly busy with their own families. It was unlikely that we would get any help from our church. It was all overwwhelming.

When we turned up our road, we realized how much worse the storm had been in northern New York even though it caused plenty of trouble farther south. Great white walls higher than a person lined the road on both sides. Most of the snow banks in front of our house were hard-packed lumps as big as boulders, reinforcing the wall in a great wedge and spilling into the road. The momentum of the plow had thrown great heavy hunks of snow several yards behind the wall. There it lay, the great white wall guarding the virginal expanse of snow which glistened around our house, impervious and beautiful in the moonlight. It was 3:00 A.M. I wanted to cry, but nothing would come out. There was not even a place to pull off the road. We would have to back down the hill and use a neighbor's drive in which to park. Then we could begin the long, physical assault to gain access to our house.

It was February of 1966, and Jeff was four-and-a-half years old when we began the "patterning" program. Some of it was an eclectic assortment of activities which have long been used by educators to foster motivation, readiness, and various skills. The mention of this fact seemed, surprisingly, to upset both the program directors and detractors. Lots of reading aloud was advised—poems, nursery rhymes, Dr. Suess books, and short stories. Lotto-type matching games requiring visual discriminaton and eye-hand coordination were suggested, as well as simple puzzles, talking, making noises, playing sound-effect records, and tickling, as well as other sensory play. There were more exotic activities as well.

Our morning was to start bright and early with a "salt glo" for Jeff. This was done in the tub and consisted of rubbing a paste of table salt and water over his lower extremities and buttocks. The paste was applied in small, firm, circular motions in a strictly prescribed pattern starting with his toes and the front of his foot, then the toes and the back of his foot, continuing up the "shank" in front, the inside of the shank, the back of the shank and the outside of the shank, the thigh (in somewhat similar fashion, inch by inch), and ending with the buttocks outward from the base of the spine and up toward the waist. Then Jeff was to be sprayed thoroughly with cool water, then with warm water, and then with cool again. Rubbing alcohol was to be applied over the entire area before thorough drying and powdering. They advised buying the salt in quantity, 100 pounds at a time. I ordered a case of alcohol, too. I worried that the pipes from the bathtub drain would corrode with the daily doses of salt.

We were to cover Jeff with a plastic mask over his nose and mouth. An interior portion retained some exhaled carbon dioxide. It was theorized that in just the right amount the carbon dioxide would trigger emergency supplies of oxygen to all of the body's organs, including, of course, the brain. It was additionally noted that deeper breathing patterns and better use of the lung capacity would result in overall better health and a decrease in respiratory infections. The masking was to be done for precisely 60 seconds, 18 times a day, scheduled at 30-minute intervals. Furthermore, no one was to be allowed to smoke in the house because of its adverse effect on the air and therefore on Jeff.

Two hours of crawling were expected every day, half an hour after each pattern to reinforce it and to allow the body the maximum opportunity to "give back" what it might have absorbed during the pattern. Additionally there were lots of games, mostly invented by parents, to encourage the children to crawl. "Crawl" was obviously the name of the game.

There were other requirements, many specific to each child. For example, we were to have blinking colored lights in various places to attract Jeff's attention. All of the Christmas lights were dragged back out of the attic and blinked conspicuously into spring and summer. I hunted vainly for red cellophane and finally bought a box of Valentine chocolates to obtain its precious red wrapper. This was put on various pen lights for eye exercises. We were to begin at the bridge of Jeff's nose and slowly move the light away to a prescribed distance and then turn it off before repeating the procedure several times. These exercises were to be done at intervals five times during the day. Additionally, Jeff was to watch a blinking red light precisely three feet from his eyes for five minutes at least twice a day. The light was to blink at five-second intervals. I thought I would go blind or crazy blinking the damned thing and could not see straight for a half hour after emerging from the darkness. Finally Carl rigged up a motor to blink the light, and I was able to leave Jeff alone to his "treatment."

We had to make flash cards of commonplace and conspicuous objects and tape them all over the house, thus labeling walls, windows, refrigerator, beds, telephone, tables, chairs, and the like. A friend made additional cards, and in all we had a couple of hundred words Jeff was supposed to learn by sight recognition. We were to hold a word up several times a day and repeat it, and evaluate his progress by having him choose that word from one or two other words.

For some reason he particularly hated this activity and, after moderate initial attention, turned his head swiftly away and refused to look at or to point out words. Sometimes he indicated the word correctly and sometimes not. Carl and I were pushing the patience of an actuary trying to figure out whether or not Jeff could "read" after factoring in the laws of averages on his pointing to the right word. Our answer was always a qualified yes, and we were at a loss to know why Jeff could tell us a word one time and not another—no matter what bribe or threat was used.

There were other activities too, such as banging pots and pans, running the vacuum cleaner near Jeff, banging blocks of wood together, and playing the sound-effect records. Jeff had a strong startle reflex which made him jumpy at the sounds. As I understood the intent of the activities, this gross reflex could diminish with exposure. We would have been profoundly grateful for that. It was discouraging to have Jeff flip a whole mug of milk into his face and all over the kitchen when someone turned a light switch or the phone rang.

Auditory discrimination could be increased by exposure to various sounds. This was thought to be a help in learning spoken language. We felt that spoken language would be the greatest single blessing Jeff could receive at this point, for we wanted to understand his frustrations and his needs. Furthermore we felt that people, including doctors, seemed to judge Jeff's intelligence by his lack of spoken language. We were willing to try almost anything to achieve this goal.

All in all, just thinking about the demands of the program put me into a hyperkinetic state. At night I would wake up and think the whole venture unreal; we could not embark on such a bizarre endeavor. Still, we worked night and day to ready the various pieces of equipment and to find enough volunteers. My neighbor Joyce Silva called up and down the road inviting people to an open house. We served coffee and donuts and I explained the program in great detail, giving excerpts from the lectures and explanations as I understood them. Finally we demonstrated the pattern. It required three people, one to move Jeff's head and the other two to move an arm and a leg, standing at his sides. The first attempt was a disaster, and it required an act of faith to believe that this could ever be worked into a perfect, rhythmic pattern worthy enough to be impressed upon Jeff's brain. In one woman's face I saw the sure and certain horror that we would brutalize him in this fashion, the same mock sensitivity my mother exuded when I stretched Jeff's ankle tendons in her presence. "Oh, I could never do that!"

Having been hurt by the attitude of our would-be babysitter's mother and the many comments I heard directly or secondhand, it was all I could do to ask these people. We had been literally rejected so many times and in so many places, by people who were being well paid and in fact existed for no other overt purpose than to help people like Jeff, that I was actually scared to approach people further. Miraculously, every person there expressed an interest in Jeff and wanted to help. Even the woman who declared she could not, sent her daughter. Most of them spoke directly to Jeff in a way which professionals never did and were not overly bothered that he turned his head away or did not answer. The big comment of the day was, "Oh, he is so much better than I expected." Carl and I had a great many small laughs, loaded with relief and gratification, remembering the reactions. We knew only too well that Jeff had every defect in the book, but we reveled in the knowledge that he was just a little boy to these people. It had been so long since anyone had noticed that.

To enhance the healing that this expression of concern brought, I received a telephone call from a young woman offering a team of three patterners, when I had all but despaired of finding the last two. My friend Joyce Bowers volunteered to coordinate the patterners. This was a tremendous job and involved finding substitutes for regular or vacationing patterners, as well as informing the patterners of any cancellations or changes in our schedule. In general, Joyce's job was geared to keep me off the phone and to leave my mind and time free to deal with the other aspects of the program. My neighbor and good friend, Joyce Silva, took no permanent spot because of her substitute teaching, but spearheaded the effort to rally neighbors to our aid and filled in often on weekends and during storms when our road was inaccessible. My brother patterned with Carl and me on Saturdays, and Carl's brother and sister-in-law came every Sunday after a long and hectic morning at Sunday School and church with their own youngsters.

If unknown neighbors and friends shared our hopes and enthusiasm, everyone did not. My friend Jacquie called and asked if we would be home. I had never seen her so upset as when she arrived. She tried to talk me out of the program. I was shocked and hurt. I had done all that I could to get Jeff traditional treatment and therapy. Short of signing the blanket permission and enduring the physical separation required by the Shriners, I could not see any way at all. I had followed through with every suggestion and every opportunity and had begged for more. No one, I thought bitterly, could have known better. Jacquie was adamant. An ugly tension hung between us. She pointed out that Jeff's medical prognosis had seemed very grim and that the doctors probably expected him to die. This only increased my fury.

I pointed out vehemently that our kids do not always oblige by dropping dead, and that it was us, the parents and the children, who were left holding the bag. I resented that doctors could get away with playing everything from God to clairvoyant with perfect impunity, while in fact they were not even accountable for their medical skills.

After reviewing the steps Jacquie and I had both taken toward trying to secure treatment and bracing for Jeff, Jacquie asked whether I would still insist on trying the program if she could arrange something, somehow. Angry as I was, I had to stop to work it through. First of all, I simply did not believe that Jacquie, although a physical therapist, could get Dr. Danforth, the orthopedist, to change his mind about treating Jeff; and I knew there was little use in finding another orthopedic doctor because I had already tried. No one would even see us. There was no doubt that Jeff's retardation was the factor that most prejudiced them and allowed them to be comfortable with a double standard of treatment. Apparently retarded children were an entity unto themselves. The fact that these physicians were themselves retarded in their understanding of human growth and development did not trouble them. That is precisely the way they wanted to keep it.

I thought of how it had been the happiest day in my life when I saw Jeff stand and heard that he would be given a chance to walk. I thought about the numbness, the leaden depression, and the terrible hate that had consumed me since Dr. Danforth had succeeded in snatching that chance from Jeff. I knew I could not live through another such disappointment.

Finally I had to answer no, I would not defer the program any longer under the circumstances. I cringed inside when I remembered the coldness and condenscension with which Dr. Danforth touched Jeff, and my eyes filled with tears and my throat closed with anger. No child, no person, should be hurt inside the way that man had hurt Jeff and me. I knew I did not want to beg for that cruel indignation anymore. I wanted people, real people, to touch my child with the beautiful, clumsy, loving hands which the patterners extended. I wanted them to touch our lives with their concern and to heal us all. No, for everything there is, indeed, a season. We had spent ourselves, and now we needed someone to confirm that our son was worthy of all the love and caring we could give him. When Jacquie left, there was a distance between us which had never existed before and which I supposed might never be bridged completely.

We began the patterning program in earnest. Jacquie, perhaps feeling the rift as acutely as I, went to observe another child who was being patterned at a nearby public school and ended up patterning herself. With her typical decency, she announced that the mother was pleased, the principal was pleased, and that all in all she was not about to discount their opinions in the matter. Furthermore, she drew out the similarities to range-of-motion exercises and allowed that performing them in an established developmental pattern should not hurt, providing everyone was carefully trained. This allowed me to feel better, which again was characteristic of her.

If Jacquie was to confer a limited blessing to our venture, however, the local executive director of the cerebral palsy school was just taking up the cudgel against us. A couple of our patterners called to say that Ms. Houston advised them not to take part in the program. One of them gave me a copy of the official statement by the American Academy of Pediatricians' Executive Board which Ms. Houston had been handing out. The statement was very negative in spirit, although words were measured. It pointed out that no controlled studies were available to support the greater value claimed for the program versus conventional programs. It obviously presumed that parents had a choice—that, in fact, conventional programs were available to those who wanted them. From my own experience and the numerous tales of total disregard I had heard from other parents, I found this naivety astounding! "Without such studies," the statement continued, "a medically acceptable evaluation is not thought possible." But that was not going to stop the Academy from giving an opinion nonetheless. They felt compelled to do so because of "the demanding nature of the program and its seemingly unreserved promise of benefit." To underscore this, they quoted Dr. Downing as saying that "preliminary results were encouraging." The more I looked the statement over, the less threatened I felt. To my mind it was disappointingly lacking in logic. It conveniently ignored the gross failures of the present medical care delivery system and seemed unaware of the empathy which causes other people to support such a demanding venture. I decided to post the statement in plain view of the patterners so that they could decide for themselves what their position would be. The investment in time and caring they were making entitled them to a view of both sides.

One mother commented, "I'd hang my kid upside down fifteen times a day if it couldn't hurt, and I knew it might help. Don't they understand that?"

It is impossible to imagine our surprise and joy, when after a couple of weeks of patterning, Jeff started to talk, to count, to recite the whole alphabet and all kinds of rhymes, and to say his prayer every night. The prayer had been heard by him for months and years and started with the prologue "Jesus, bless our boy." It continued with the traditional "Now I lay me down to sleep" in the first person, in the vague expectation that someday he too would pray. Automatically I added, to the ever-increasing list of special people we wanted to remember, the words "and all the patterners who try to help me." Jeff had heard this phrase only a few times, but he included it as he labored through the entire prayer. We knew that his speech was clearly of a rote nature, but it was a profound and almost heartbreaking joy to have his tongue miraculously unleashed!

Our little girl Julie was also growing by inches and pounds. She crawled with Jeff, and was so active that we missed the joy of ever seeing her tentative first step. In fact, if there was ever anything tentative about Julie, she indulged it alone. We never saw it. I wrote in her baby book, "Walked at nine months—stopped only by her curiosity," meaning that one could never tell for sure if she was about to fall after ten steps or not, because she always seemed distracted by something else. She plopped herself down without ceremony to investigate with equal vigor a patch of sunlight, a mark in the tile, or an insect.

Our pleasure at seeing her walk was marred only by the frustration and pain it caused Jeff. During her first months they had been close, sharing the same room and the endless floor. Julie was a great therapy for Jeff. He was quite used to dragging himself off to the most remote corner of the house, and sometimes my back and arms ached with the effort of retrieving him to try to expose him to the action. Sometimes he threw violent fits if a child so much as extended a toy to him. His lack of congeniality seemed more by calculated choice than from dullness. He preferred to be left alone. This both hurt and troubled me. I felt a little reluctant to intrude upon his desire for aloneness, but I also felt he would never develop or improve in any way unless we could retrieve him from his private world.

Julie, on the other hand, was not bothered by any guilt, neurosis, or hang-up which prevented her from dogging him every minute of the live-long day. Everywhere he went, she went, chewing on his toes, crawling over his back, feeling his nose. Our beautiful basset hound Macquie literally quit the house for the love of Julie. Jeff, however, had no choice. First he ignored her, and finally he tolerated her. His aloof, disinterested manner beliea his dependency. He always smiled or laughed when she was about to get into trouble, though he never looked at her directly. Often a patterner would remark, "Look at that. He knew she was going to pull that off. Did you see that little smile? And him pretending not to notice her!"

What's more, if she did not get in enough trouble on her own, Jeff could always think of something, either crawling to the toilet and opening the lid or, with extraordinary patience, opening the fireplace screen so that she would go in. Then he would sit back and enjoy the action as Julie bent deep to the task of slopping every last drop out of the toilet bowl or covering herself with enough ashes to shame a chimney sweep.

So, in their own ways, they were comrades in adversity and touchingly close. When Julie began to stand, Jeff would swiftly pull himself over to her, arm over arm, legs wobbling out behind. He would pull her down by her britches, and if she would not stay, he would try to hold her first with his arms. If all else failed, he would pin her with his whole chest. It was as if he realized that his entire way of life was threatened by her walking. It was a poignant time and I felt sorry for both of them, but I let them work it out with a minimum of interference. He had to know that he could not keep her, and she had to learn that she was equal to going.

In the meantime Jeff had learned to climb in and out of regular chairs and to reach over and turn on the record player. There was nothing he liked as well as winding an airplane propellor, pumping his top, or watching a turntable spin endlessly. Even though he could have no music in the patterning program, we bought records of spoken stories—everything from Dr. Seuss to *Treasure Island*. Characteristically, Jeff put up a horrendous fuss when we put a new record on. He would scream and cry and beat the floor with his hands, and even hit his own head. The veins in his neck would become tortuous.

Sometimes we had to laugh at his unreasonable fury. We had spent so many years feeling inadequate, guilty, apprehensive, and angry that all of a sudden his reaction seemed funny to us. It was, of course, a great ego shatterer to have a gift recording acknowledged in such a manner, but for the most part people were tolerant, if more than a little surprised. We tried to avoid the scene by accepting the present and assuring the benefactor that we were sure Jeff would love it, smiling to think of the horror which would ensue first.

And he did come to love all of the new stories. I embarked on a deliberate plan to play the record two or three times in a row, to avoid the possibility of so many tantrums, but allowing him to vent himself in any way he wanted. About halfway through the second time he would uncover his ears or take the rug off from his head and listen. At that point he might offer a few screams or a mini-tantrum, but the full fury was past, never to return again. Next he would pull himself out of his room, and after the record was over, he might even point to the record player. He soon learned the words, "Make it go again" and developed code names for all of the stories. His speech was not always clear, and he sometimes chose words which did not immediately relate in my mind to a given story. But it was worth the effort to understand him. Jeff was beginning to join our world.

He also learned to climb stairs with the use of his arms only. This was, it seemed to me, an incredible feat of strength, judgment, balance, and coordination. It occurred well before the patterning program began and increased our feelings that he would be strongly motivated to begin walking with braces. When I mentioned this feat to several doctors, they shrugged it off summarily, as they did Jeff's other accomplishments. I guess if you insist upon using a stereotype of "normal" for your standard, anything Jeff has ever done is wholly unremarkable. In my more charitable moments, I feel sorry for those who have lost the ability to look at people as individuals and to be moved with wonder that a little boy could work so hard to use so exquisitely the resources he had. I saw that as his body and legs were lengthening, he would no longer be able to mount the stairs, and it broke my heart, for there would be no new physical feat to make it up to him.

Surely it was more obvious than ever that Jeff would never walk without braces, and it was not at all likely that we would even be able to "smarten him up" to the cruel standards of the Cerbral Palsy School, which not coincidentally was located at the rehabilitation hospital. And this, in all my inquiries, seemed the place most likely to accept him. Such were my complaints to the visiting health nurses who came in to check on Julie's development and care. Julie was not the one who needed help.

Finally, with the help of these women, we were able to secure an evaluation at the rehabilitation hospital with a physiatrist, a doctor specializing in the diagnosis and treatment of disability by physical means, such as braces. In this way it was hoped that we could circumvent Dr. Danforth, the orthopedist, although we would end up back in the same hospital and clinic. Meanwhile we were maintaining the full program schedule, including patterns, and arranging for surgery on Jeff's eyes in New York City, since we could find no one to do it locally.

After patterning a full year, we tried to reevaluate our total position. Jeff was remarkably better in many ways, but not so improved as any of us had hoped in the beginning. The evaluator at the Institute in Pennsylvania seemed to think that Jeff was a lot smarter than he was letting on, and sometimes I though so too. Most times he simply would not try, so that it was difficult to know whether he could not or would not. We had conflicting external opinions, and were confused at our own observations.

I read an article on autism which seemed to describe Jeff perfectly. This set off a whole new area of inquiry. We made a series of early morning appointments as private clients at our local child guidance center to have Jeff evaluated by someone totally independent of the Program.

In the end the patterners stayed with us for several more months while we had Jeff's eyes straightened, and endured a long, cruel hospitalization requiring two additional surgeries in Philadelphia involving his shunt.

Through it all, the patterners came and helped just because we needed them, and in hopes that they could do something decent for Jeff. We tried to keep them honestly appraised of the situation, and they never questioned our decisions. They trusted that we were doing the best we could with the resources we had.

We, as much as Jeff, learned from the program. We learned to trust and love people. We learned to hope anew: not in wild, unrealistic ways; that was not our style; but to hope that we could feel good about ourselves again. We learned that we could not be so self-sufficient as we had been brought up to believe people ought to be; and we were deeply grateful that people understood our desire to invest in our child, and to do that with us. For it did mean a hundred sacrifices for each of them. Knowing this did not make me feel indebted, as the doctors seemed to fear, but rather it seemed to free me.

For the first time I could look at other women with real respect, to understand the goodness and zeal and the commitment to sometimes tedious tasks which often characterized their existence. I came to respect the ingenious ways in which they took the monotony out of what had to be done. I had always shied away from coffee klatches and long telephone conversations as a phenomenal waste of time. Finally I had to see that, whether I liked it or not, this was the way real friendships were built, with real attention and time. Much as a garden requires the tedious tasks of weeding to enjoy the flowers, so real friendships need constant attention to bear their best fruits. I knew, too, that the activities of these women enriched every member of their family. I had not given myself to these ways of building friendships, and it was partly my own neglect as much as Carl's withdrawal and other people's discomfiture which contributed to our desolate situation.

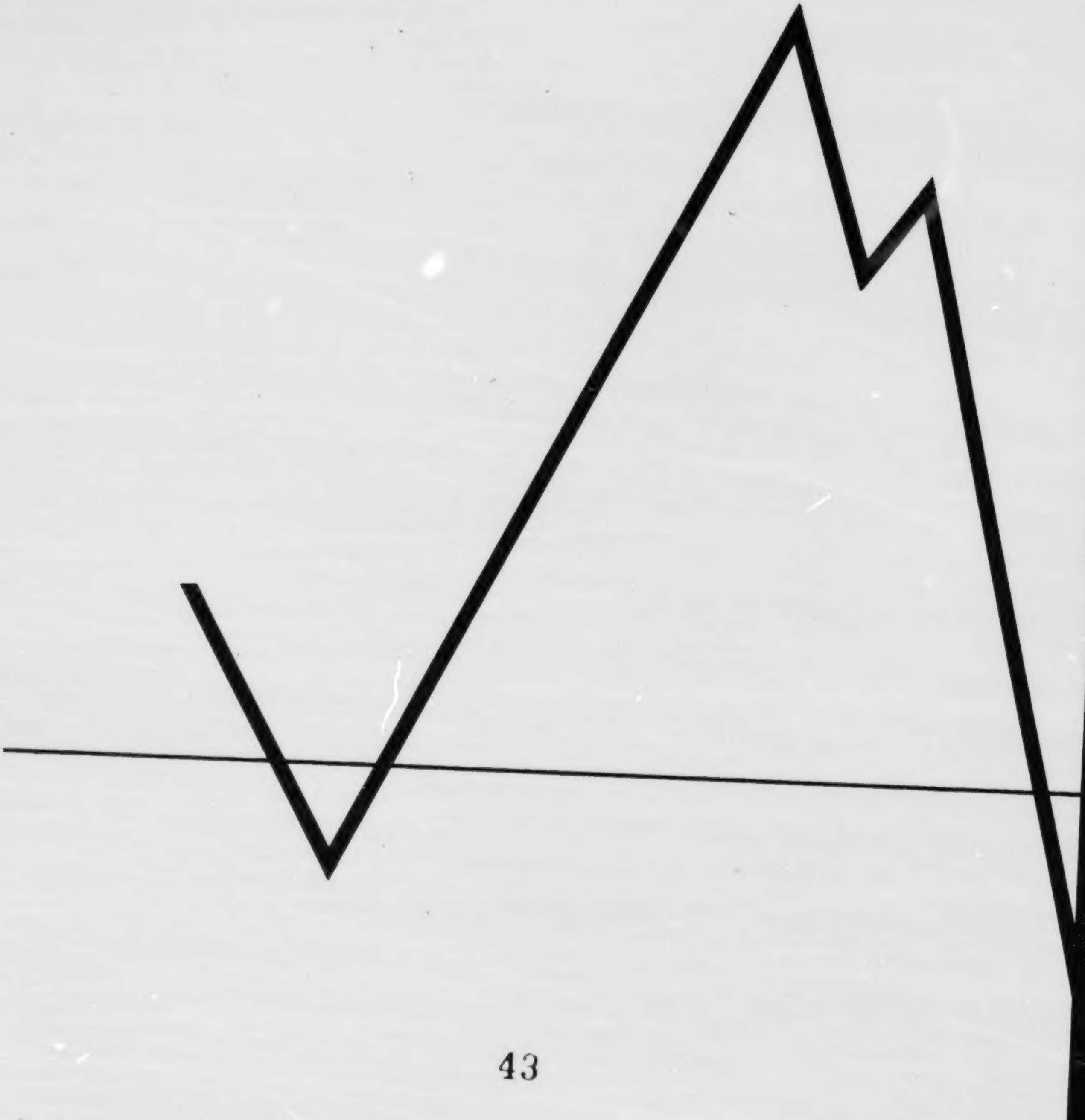
Another result of the patterning program was that, with a modicum of hope, some specific responsibilities, and other people modeling an investment in Jeff, Carl began to show more interest. He signed up with me for a course in the principles of language development. By now one of the patterners had suggested, on her own initiative, that her daughter would like to baby-sit and could handle Jeff. Thus, we went every Wednesday evening together to the course.

We also learned that if a need could be structured and broken down into specific, time-limited responsibilities, people would respond in heroic dimensions. The same situation which created endless discomfort among friends, neighbors, relatives, and church people inspired generous response when structured in ways people felt able to deal with. People who would not set foot in our house, fearing that we might be jealous of their normal children, came faithfully for a hundred weeks on end. The church which had failed us painfully recruited patterners and a coordinator for the second year.

This interest in us, this sharing in the growth and value of our child, helped to validate our own feelings for Jeff. I started taking an evening course in learning disabilities in Albany. Instead of feeling shamed in my quest for knowledge and involvement in Jeff's fate, I indulged my gut responses. Carl gained psychological permission to invest himself, too, and began to help me strategize and plan for Jeff's future.

We grew in a hundred ways from the gift of time and concern our friends brought in their hands. And the very practical advantage of a steady stream of baby-sitters was to be ours, beginning with Michelle. In some cases these young people made career decisions directly attributable to knowing Jeff. In all cases we felt good to know that the mothers who patterned Jeff were happy to have their daughters, like themselves, reach out to our children, and to us.

Chapter Six
Testing, Schools, and Programs



Jeff's behavior and mental development were a heavy concern for us. The pediatrician had, early on, informed us that we might expect brain damage, that such damage was irreversible, and that Jeff's subsequent behavior might change in bizarre ways for "no reason." Perhaps this statement from authority in the presence of my own ignorance and thirst for information actually colored my interpretation of Jeff's behavior.

I can never remember questioning that Jeff was slow. Nor did I deny that he was "retarded," except when I read authoritative definitions; Jeff did not seem to fit the definitions. I do not recall feeling guilty or stigmatized about his condition. Not that I didn't feel the stigma other people projected upon me and my child. I did; very early. And I was, and still am, hurt, angry, and impatient at that. It is unfair to judge a child's value by what some person or other considers to be intelligence.

When the psychiatrist asked me what I expected Jeff to be like in ten years, if he were to live, I said it all depends upon what happens between now and then. I explained some of the ways Jeff was normal in his intelligence and thought that if our skills were sophisticated enough, we might learn to build on his competencies and fill in his deficits. But we needed more information. Jeff needed respect and the opportunity to be with other children in settings where he was expected to learn. I accepted that he was slow, but I did not know if I could accept the fact that he had no useful speech. For my own sake I needed to hear my name, to feel some better communication, and to know his needs. Without this I was almost distraught trying to figure out what was wrong with him at times. I believed that was a realistic, if challenging, goal: speech for Jeff.

Later, when Jeff was hospitalized in Pennsylvania, I met a boy who was about fifteen. Richard was able to talk, and sat mostly alone in his wheelchair, looking for someone to visit with. I gravitated toward him instinctively. I felt that, within present expectations, this was a good indication of Jeff in a few years. Richard's language was superficial by my standards, and at times I could not follow him. People avoided him. He bored me, and I did not prefer to be with him but rather sat out of concern, not pity; out of deep concern for his loneliness and deep shame for my inability to truly enjoy his company. I felt it was a deficiency in me that I could not appreciate this young man.

After a while it got better. Like sitting with my grandparents, rocking on their glider, imperceptibly, when I wanted to race and run and jump. As the years went by I sat with my grandparents because I wanted to, and felt content that no significant conversation passed our lips. Communication was not all head stuff and talk. But I understood, too, that Richard was pimpled and unattractively whiskered here and there. I knew only too well that he was not acceptable to the world at large. This was, I knew, my dilemma as well—to change Jeff as much as possible, and to change the world for him with at least as much vigor. He would not always be a rosy four-year-old with firm, fat cheeks and flawless skin. And, of course, lots of people were not so enamored of him even then as we were.

People seemed to view my unwillingness to accept Jeff's "retardation" with ill-concealed impatience at times. Once when Jeff was about a year old, we went to visit friends in another city. At one point Jeff let out an animal sound and nearly ripped a shank of hair out of my scalp simultaneously. Psychology aside, I cracked him on the bottom. My friend chided me that I would make him "too submissive."

By then I was used to every kind of advice, and I resented most of it. When a child does not develop "right," everyone wants to get into the act. Some people assured us that Jeff was perfectly normal and just a "late talker." Some people looked at him with outright revulsion and suggested that we store him away somewhere in an institution. Others offered, sometimes in his presence, that "he'd be better off dead." My friend was shocked that I did not seem to understand that he was retarded and gave me a book with the traditional set of IQ ranges for imbeciles, idiots, and morons.

All of this I read, and lots more. But I just could not relate anything there to our child. Either the definitions and descriptions of behavior were all wrong, or we did not have a retarded child. And if not retarded, then what? Mentally ill? Everything crossed my mind, and I agonized over each thing in turn, trying to fit my child into some mold and trying to accept it for the sake of other people. I do not know why I did not realize sooner that most books dealing with the subject should be thrown away for the havoc and failure they cause. But perhaps I was enamored of professionalism and, in my desperation, discounted the sense I had.

Nowhere did I find practical ideas for helping Jeff progress and for changing his bad behaviors. Nowhere, until we started the patterning program, did I even hear this validated as a worthy goal. It was the old either-or story: either he is normal, in which case he is O.K., or he is retarded, in which case forget it—nothing can be done. It was this wholly irrational position by supposedly intelligent people which I could not accept. Everything within me said this is not sensible.

But it was an uneven fight, and to defy any authority, divine or earthly, leaves one with a sense of sin, and therefore guilt. The attitudes and practice of professionals have left their mark. And the lay public, like myself, often defies its own sense by listening to and supporting hurtful philosophies in the name of knowledge. This added tremendously to our sense of confusion and frustration as we looked for help.

Many of Jeff's behaviors were very strange. For example, he learned to handle a bottle at the usual age and eventually, like a lot of children, used it for pleasure as much as for drinking. I tried to get him to drink from a cup, and he had no interest. On the other hand, he wielded the bottle with great aplomb. I became careless about keeping track of it, and would find it laying around. Once I handed it back to Jeff, turned to leave, and felt something wing by my ear and land a good five feet away. The violence with which the bottle hit the wall left nothing to the imagination. At the next meal he accepted his cup, drank like an old pro, and never mentioned the bottle again.

Likewise, we had trouble with the spoon at first. Jeff could dip it in, scoop up food, and carry it to his mouth. At that point he would stop dead and sit in frustration for minutes. I tried everything—standing behind him and guiding it in, leaving him alone with cereal when he was hungry and pretending to be busy with my wash—but nothing worked. We called it the Gardol shield after a commercial which featured an impenetrable protective glass. Meanwhile he continued to zero in on errant pieces of rice and eat other foods with his fingers. Finally, in Jeff's presence, I described it to a friend whom Jeff liked very much; he never did it again. Another time, with Jeff listening, I mentioned in desperation that Jeff always cried and threw a terrible tantrum at a particular spot in one of our recordings. I played the record to see what she would make of this behavior. Not only did he not do it, but he never did it again.

When he was nearly one, he took to "oinking." We had no idea why. Visiting Carl's brother and his wife, we told with glee how Jeff could say three words, "Momma," "Da," and "oink." Eleanor was delighted and pinched his fat little legs, saying, "So you're a little piggy, are you?" Before we left for church, we joked that we hoped Jeff would not oink during the sermon. Right on cue, during a lull, Jeff presented his swan song of oinks to a crowded church. We never heard them again.

These kinds of occurrences could not have been better calculated to have us distrust our own sense of reality. Once my mother had taken care of Jeff for two days so that we could go away together. When we were all together again, Carl sat reading his paper, I sat with a book, and Jeff sat on the floor swaying to maintain his balance in the splint pillow.

"Shit."

Carl looked up. I looked up. We did not believe our ears. Jeffy did not talk. We must be hearing things. Not our mute son, swearing.

"What did you say?" I asked, in no particular tone except disbelief. He did not say another word for months.

Once when he was hospitalized in Pennsylvania, Dr. Spitz's surgical nurse stopped me outside of Jeff's room. "You should hear what your little guy told me this morning."

"I'm Mrs. Pieper, Jeff's mother," I explained, as if that should be sufficient for her to recognize her error.

"I know who you are," she replied.

"But Jeff doesn't talk," I informed her as we stepped into the room.

"Oh, yes, he does," she twinkled, her eyes darting mischieveously between us. "He told me his mother said he doesn't have to eat his lunch if he ate a good breakfast."

I was astonished. Jeff had not eaten well for a couple of years. His menu was bizarre—peanut butter, grilled cheese, spaghetti, Silva's meatballs from our neighbors' restaurant, chocolate milk, tea-milk, french fries, and a couple of cold cereals. He was painfully thin, the subject of comment by every intern who examined him. (He was also healthy and strong.) We insisted that he try everything on his plate. Sometimes Carl, who was perturbed by Jeff's finicky habits, shoved the required taste down him. The truly astounding part was that Jeff had told this young woman what I felt, though the words had never passed my lips.

Jeff seemed to have a lot of insight in some ways, and it was easy to think he was putting us on, as the evaluator in Pennsylvania kept telling us. There was no question that Jeff could count the chimes of the clock when he was four. I remember the first time I knew he could count on an associative basis because I was throwing sugar into egg pancakes, and deliberately put in two extra "short" spoonfuls to be sure of the phenomenon. He always knew what day it was by what patterners showed up. Although it was virtually impossible to figure out how many words he could read because of the guessing factor, we knew he could read some. (We also laughed to see Julie return cards like *telephone* to their proper place at the age of two when it was pick-up time.)

Finally, after a year of the patterning program, Mr. Martin, the evaluator, was at the end of his own patience in testing Jeff. At one point when he could not get any response out of Jeff, he slapped his face. This was painful to see, but we did not protest: first, because despite our deep doubts about how professionals were treating us and our child, we were trained to be quiet, respectful people; secondly, we had no alternative. We were at their mercy. We needed to know what was going on with our child, and if the professionals could not find out, then we were the most hopeless of people.

After the slap, Jeff began to wave his arms wildly. Mentally I saw him retreat into "never-never land," as we called it. We asked if something physical might be going on—small, intermittent seizures, for example. We felt we had to know if Jeff could not, or would not, learn and respond. This seemed crucial in order to determine what to expect and how to treat him.

The subsequent electroencephalogram, or brain wave test, showed no evidence of seizures. I began to suspect that if Jeff had ability and directly thwarted our attempts to help him, he must be emotionally disturbed or at least bent on making me an emotional wreck.

Certainly he evidenced all of the behaviors I had read about in conjunction with autism. On the other hand, I got to know families with autistic children and began to suspect that most of the information on the subject ought to be discarded. In no way could I believe that these mothers, all with other normal children, had created such strange-acting children as well. No, there had to be many causes for autism. It could not be one disease. Probably many physical conditions, like Jeff's erratic pressure, combine to cause the initial trouble. Societal attitudes and the subsequent stress on families may underwrite the peculiar behavior. What we needed was help getting interaction going in positive directions, not the finger of blame. To that end I joined our local Society for Autistic Children.

All of this working though meant lots of reading, attending meetings, taking courses, meeting people, and trying to integrate what seemed valid. While I read Dr. Bettelheim, I bought Jeff a Raggedy Andy doll, which was the only boy doll I could find. He threw it down the stairs over and over again, shrieking with wild laughter, "Andy boke [broke]. You boke him." I was terrified to broach the subject for fear of doing more harm than good, but finally I asked, "Do you think Mamma broke you, Jeff?"

"Yes. You boke him," he said as he looked soberly into my eyes.

How would you explain the situation to any child of five, whether or not he was "intelligent"?

My heart sank, and in my mind I heard more societal and psychiatric injunctions about handling things poorly and causing damage to the child. I was terrified.

"No, Jeff. Momma loves you. I did *not* break you. When you were born, your legs wouldn't work. That is the way you are. You are not broken."

In my heart of hearts, I was afraid that Jeff might think of me as a monster. One morning, I strode into his room, kissed him good morning, flipped the shade up, and heard behind my back, "You're a big, big monster."

I approached his bed. Standing close enough so that he could touch me, I said, "Hit the big, big monster." Without hesitation he hit himself.

I began to understand that he was very sensitive and easily threatened psychologically, for all his tantrums and physical bravado. Also he was calling himself "He," "Jeff," and "you." He never used "I" or "my" until one day when he let out a short squeal of pain. Running with the expectation that Jeff would have to have three fingers wrenched clean off before he made a sound, I saw him grinning. Julie sat like a curious toad nearby. "What happened?" I inquired.

"She pulled my hair," he informed me brightly, getting the whole thing right so that there could be no mistake.

I prevailed upon Sister Lucina, a nun from whom I was taking a course in learning disabilities, to test Jeff. The afternoon ran amuck when we deliberately turned off the thruway at Albany instead of continuing on toward Philadelphia. Responding to a change in our accustomed routine, Jeff screamed, "Dr. Fitz, Dr. Fitz" all the way to the colege, where he became extremely withdrawn. Sister even allowed us to bribe Jeff with lifesavers, but he was unresponsive; despite her patience, I was not sure of the results.

Afterward I was angry and bitter. I felt we still did not know what Jeff could do but only what he would not do. I was afraid we would never know what his specific deficits were and how we could strengthen particular areas of learning or performance.

Jeff looked at my face intently, something he only did since his eye surgery. "Mommy, you look sad," he announced.

"You're darn right I'm sad. And I'm mad too. You wouldn't do anything," I blurted out at him.

"I did the cat," he pointed out, nice as you please, even using the first person. And he was right, it was the only thing he had done, and he did it quickly and well.

Even before we had Sister Lucina test Jeff, we had taken Jeff to a local psychologist recommended by the psychiatrist. We had not done this immediately because of Jeff's shunt troubles, Julie's birth, and the decision to pattern. But after a year we wanted an opinion independent of the Institute program. The man was someone Carl and I liked immediately. He treated Jeff with respect, and we felt he would be honest with us. He took time with Jeff, allowing me to sit in on most of the testing. In the end he said that Jeff had scored 36 on the Binet. He guessed Jeff had an I.Q. of about 50 or less, taking other observations into account. Again, we did not rail or flay, only pointed out the type of performances that seemed to give us more hope. He did not think that continuing the patterning program would do any good, and he was not surprised that no area preschool would accept Jeff. He was unfamiliar with resources for retarded children and apparently considered referrals and the existence or nonexistence of real educational services beyond his professional responsibility.

He, like so many other professionals, was disappointed in us for not "accepting." And yet within this kind of disappointment is a certain smugness. After all, we are true to the profiles and the predictions which parades of professionals have trotted out. And yet they do not understand what we are rejecting: it is the attitude that labeling is enough, that a pat on the head for a job well done is sufficient. We often know before we go that our children will never be "normal." We already love and accept them on a day-to-day, minute-to-hour basis. What we cannot face is that the rest of the world will not and that the verdict "retarded" is almost synonymous with a sentence to oblivion and neglect, the end of the road.

I think, too, that most parents know instinctively that how much a child progresses depends upon the nature of our response to their needs, the kinds of experiences they have, the ways they are treated, and with whom they come into contact. Therefore, the label of "retarded" starts out being functionally useless and ends up diminishing our already small chances for a better life for our children. We are continually adjusting our expectations. But we reject the labels and attitudes which seem dangerous for our families.

The patterners helped me keep my sense of balance relating to Jeff. They enjoyed him for what he was and would not allow me to go too deeply into thinking about the sinister psychiatric implications of his peculiar behavior. Meanwhile, I was still taking courses, running to meetings, and attending workshops. One day I heard the Brauners, a husband-and-wife team, who work with severely impaired children in France. They took the outcasts, the Mongoloids, the autistic children, and those who, like Jeff, could not be toilet trained in the usual sense. They spoke of how they were able to reach even the most withdrawn child by composing music which especially exemplified his inner rhythm. If the child whirled all day, they constructed music to accompany his whirling. Then they used special signals, a slight pause or a dissonant chord, perhaps, to stop him, even momentarily. They spoke of teaching children to read colors and shapes instead of words. I ran home to meter some of Jeff's favorite poems and translated them into color.

Another time a nun who was a musical therapist spoke of how music could be used not to mesmerize children but to get them to do things. She recommended a book by Clive Robbins and Paul Nordoff, which I read with excitement and understanding. As she played the piano for children from a special school, tears stung my eyes. I saw spastic, retarded children come to life, not with the aimless, happy rhythm which seemed to magnify or mock their differences, but with purpose—to perform a whole musical play.

An older woman sitting sedately next to me seemed to eye me with direct interest. I felt embarrassed to be so moved by this performance. One of the boys reminded me particularly of Jeff, and it was like a miracle to see him come alive beating his drum. Intelligence and sensitivity seemed to shine from his eyes. I wanted so much for Jeff to have experiences like that. There was so much I could not give him at home. Later the woman spoke to me and introduced herself as Miss Carre. I explained our situation.

To my great interest, she empathized readily and said that she was a teacher for a class of children labeled "trainable retarded." She invited Jeff and me to come to visit them. I was giddy with excitement, figuring that this was as close as we would ever get to a public school. She gave me directions, right down to the basement room where her class was lodged. I had noticed from my substituting that special classes were often in the basement.

We talked and talked. Finally I dared to ask something which had been bothering me.

"I hope you don't think I'm paranoid, but I feel sort of set apart, too. You know, kind of a stigma. Like I'm retarded, too, because of Jeff. Do you know what I mean?"

"Indeed, I do and it's not crazy at all. I used to sit with the other teachers for lunch, and one day something came up about credentials. Someone said, 'Well, of course, that wouldn't affect you.' Well, I knew exactly what she meant—that credentials were of no importance in teaching the retarded, and that in a sense I too was stigmatized. I was quite happy to inform her that I have more credentials than any of them, that I am qualified to teach in any college in this country, and in fact did so for many years. After that I decided to eat lunch with the children. They are so much more sensible."

As I began to see valued, intelligent people expressing my concerns in their lives and actions, I began to feel more and more validated in wanting opportunities for Jeff. It was increasingly obvious that our children's ability to learn rested not only with their inherent conditions but also in our responses, in our abilities to innovate and to reach them. I began to see that this would take familiarity with technical skills as well as political action to see that the skills were available. But mostly our children's ability to learn rested in a commitment. For parents, and for many professionals too, this commitment meant being able to challenge authority.

One of our favorite patterners related a bit of news that nearly brought me to defeat, as in days of old. Ms. Houston, the executive director at the local cerebral palsy school in Rosy Sky Regional Rehabilitative Hospital, had remarked that no matter what we did, we would not get Jeff in there, since we thought he was such a genius. I could not believe it. She had never shown any interest in us when we attended meetings, and it was she who had handed out the negative statement urging people not to help with the patterning. But this was too much. The school had refused to give Jeff any help because he did not meet their standards, but when we tried on our own to help him meet those cruel standards, they ridiculed us. Every time I thought of it I cried.

By the end of the afternoon, I decided to challenge her, calling her at home. If I was uncomfortable in this decision, I had only to think of the time, energy, and investment our friends had made in Jeff. Somehow when I only thought of Jeff and me, I could take my tail between my legs and play martyr, but I could not let *all* of us down. We had worked too hard together.

To my surprise Ms. Houston was very cordial, and in fact denied saying such a thing at all. She was only quoting Mrs. Braintree, the nurse who ran the cerebral palsy clinic. I could believe that, somehow. I could not understand why Mrs. Braintree put such a premium on intelligence, however, or why she would deliberately misinterpret us after turning us away herself. Mrs. Houston vowed to keep an open mind in the matter. I thanked her with most profound relief.

During the week-long evaluation in the Rehabilitation Hospital to ascertain Jeff's chances for walking, I stopped Ms. Houston in the hall. I asked her if she had seen Jeff yet or had been able to try him in the classes. Yes, she had, but he just did not fit; it would not work out at all; he was unresponsive and retarded, and he would not get anything out of it. It would be unfair to the rest and to the teacher. I could not understand it. Every fall when a member of the board called for our donation, I would harrangue him about the school's exclusion of children like Jeff. He had told me, as did people with children there, that the school had retarded children.

"There must be lots of other children like Jeff. Isn't there any chance of starting a new class? I'd teach it. I'd do anything I could to have Jeff be with other children?"

"Well, that's why there's Newtonville. The parents wanted a class for those children. Albany takes care of that. That's their territory."

"But that's so far. I couldn't get there to credé and change him, and I couldn't get him there every day."

"You parents," she laughed. "You should just be thankful it's there. A couple of years ago there wasn't even that!" She wheeled around to reenter her office, still shaking her head in mock tolerance.

While Jeff was in for his total evaluation, he was seen by the same neurosurgeons whom we felt had neglected him woefully for four years of his life. This was contrary to our written instructions that under no circumstances did we want that particular team to see Jeff. We would be happy, we said, to supply any information from the Philadelphia neurosurgeon we now used or to have someone else see Jeff. But all of the area neurosurgeons were tied in to one office. Besides there were "ethical reasons" which, the physiatrist said, would force us to have the upcoming tendon surgery done by Dr. Danforth, the same physician who had thwarted our efforts to get Jeff up and around previously.

The nurse who headed the ward refused stalwartly to give Jeff his phenobarbitol and told us in no uncertain terms that she could not find words for the kind of parents that would give their child "dope." To this day I cannot find words for the tyranny which many people suffer when they have need of medical services. That conditions of dehumanization and even outright brutality exist in the name of healing with no effective redress to independent boards is astounding.

We were finally told that Jeff's hip was permanently dislocated, and that the muscle imbalance would be a severe and ongoing problem. Although his chances for useful ambulation were much diminished, the physiatrist thought that we should give Jeff his chance. We were filled with joy and gratitude. When we got home, we stood, tears streaming down our cheeks in a cold garage, holding each other and shaking our heads, unable to speak. It had been such a long, hard struggle.

After the evaluation, Jeff said something which surprised me very much. One morning as I finished rubbing his legs with alcohol, he said, "His legs don't work, do they?" Actually Jeff pronounced "legs" as *gegs* and "they" as *bey*, but I was used to these substitutions. When I asked "What?" it was to give me time to think. He repeated the question.

"No, Jeff, they don't. They really don't work the way other people's do. They can't run and walk by themselves. But if we get braces for them, you can stand up. Then you might learn how to walk."

It was hard to know what to say, but the tears that filled my eyes were as much of relief as of sadness. I was encouraged that Jeff could recognize the situation and had the sense and trust to find out about it. For the first time, I could hold out some hope to him. Perhaps seeing other people with differences and seeing something being done gave him the courage to recognize his own difference.

Jeff was beginning to deal with his world. Little by little he began watching the television screen, something he had never done before, and to look directly and carefully at Mr. Rogers. Here was a man, gentle and wholly predictable, who told Jeff he liked him just as he is, "exactly and precisely, I think you turned out nicely. I like you as you are." He required nothing from Jeff and presented no threat of failure. Jeff could not disappoint him. If anyone could put Jeff in touch with his feelings, it would be Mr. Rogers, through his music. This music was one of the few exceptions I allowed Jeff in his second year of patterning, based upon my understanding of music therapy.

When it was time for Jeff to go into the hospital for tendon surgery, after being rescheduled for months on end, Jeff began to be frightened. At the point where someone strapped the identification bracelet on, I thought he would go to pieces. Instead, his lip trembled and he bit it. Slowly and quietly I heard him singing. I could not make out the tune at all, for it was something new, but the words were small and clear: "Please don't think it's funny when you want the ones you miss, /There are lots and lots of people who sometimes feel like this." I hugged Jeff in his wheelchair, almost wishing he could just give up and cry. It was painful to see his struggle and his growth. But he had found a new Mr. Rogers song to help him identify and express his feelings.

The Mr. Rogers television program was the best therapy Jeff could have had to educate him about his feelings. At the same time it helped me to remember and truly appreciate how much children have to learn and how confusing and frightening life can be. Instead of becoming increasingly bogged down in causes and cures, my old commitment to development began to surface anew. The patterning program had helped us to appreciate Jeff's startle reflex and sensitivity to noises as part of a damaged or immature nervous system. I now began to understand and accept Jeff's self-stimulatory behaviors and gross reactions as responses to boredom and threatening situations common in childhood. Too often these behaviors are overly mysticized and presented as malevolent curses rather than the responses of children who have more to deal with and less in the way of helpful tools.

For example, I began to see Jeff's hang-up with routine as less sinister, and as a sensible response to an unpredictable world: a world which often threw him into hospitals without even the comfort of loved ones when he was already feeling sick; a world which, in turn, subjected him to pain and made him sick even when he was feeling well. Once Jeff was returned to me with seventeen needle marks in his arm, black and blue and yellow, after an intravenous study at our local rehabilitation hospital. Mrs. Braintree chided us about the fuss and denied that I heard Jeff scream for forty minutes. "He didn't cry. There's nothing to it." This probably couldn't happen in a prisoner-of-war camp, but on top of it all, Jeff's pain was denied and my concern was discounted, thus scripting us for madness. This was a polite way of saying it did not matter, because Jeff did not matter.

Jeff loved one of his patterners inordinately. The first week he called her Grandma, whom he also loved dearly. Physically Marge resembled my mother in many ways. By the next week Jeff had learned her name, and shortly thereafter became enamored of her name as well as her person. "Marge Babcock, Marge Babcock, Marge Babcock," always repeated exactly three times, was all we heard for weeks on end.

Once when I took both Jeff and Julie to a special movie, Jeff repeated "Marge Babcock" as fast as he could say it. It was, apparently, a new game to try to get the whole thing out before I clasped my hand firmly over his mouth. I would give him a good scolding and tell him that we would go straight home if he did not behave. His eyes were alight with mischief. As soon as I released my hand, he would go, "Marge Babcock, Marge Babcock, Marge Babcock," as fast as he could. Sometimes he would wait until I had really settled in, and knew I would have to make good on my threat. But I hated to waste the money, and I hated to see him get his way. I knew he would rather leave. It was his old resistance to anything new. At last I bought some candy and began stuffing him with it every time he started. I knew darn well it was dumb to be rewarding such a dirty trick. But quite a lot of times Jeff with his 36 I.Q. was perfectly capable of outsmarting me.

He did the same thing in church, repeating "Moses hit the rock, he hit it," when anything upset him. He always had trouble with his nervous system, relating to any violence or mischief with some form of excess. Not all the unchristian glances nor the equally unchristian threats muttered beneath Carl's breath could stop him. I suppose Jeff knew that the ultimate threat was to remove him, which was right back where we started. I spent years of my life trying to persuade our pastor and various and sundry other Christian educators that church was no place for a young child, that he needed a suitable Sunday School class just as other children do.

Julie brought the very point home to us by refusing to return to a nearby Bible school at the tender age of three. The patterner who suggested the school was silently disapproving when I finally relented and let Julie stay home. Much later, when she was playing choir with Jeff, I heard some strange ideas. It seems that she thought the minister in his vestments was the devil or God, and either way she was terrified. There she was, months later, still trying to work through her own fears. And yet Jeff as a four-year-old was not supposed to have any or to suffer in silence and show proper behavior.

After Jeff got his braces and walker, I followed him down the bumpy, dirt path at a camp site, cautioning him to be careful. "He's not afraid of the big, bad wolf," he replied, taking a gigantic hop forward. This was typical of the out-of-the-way things he would say. Once when the urologist asked him something, he replied with a whole paragraph from a book about Miss Suzy, the squirrel. At a ball game, a woman patted his head and asked him if he liked baseball. Jeff replied, "The baseball will eat you up." Sometimes my own nervous system came close to utter collapse as I tried to stifle my impulse for nervous laughter in situations which seemed ludicrous or threatening.

When I worked with Jeff and a language master machine, I picked up a few perceptual difficulties he was having. Upon inserting the picture card of a heart, and hearing the word "valentine" repeated several times, Jeff took up a little forward nodding. Puzzled, I inquired, "What are you doing, Jeff?"

"It's bowing time, right, Mommy?" he asked in reply.

When we crossed the bridge or watched downhill racing, Jeff would remark that the bridge or trees were going fast and look to us for verification of his perception. I could only imagine how hard life might be for a little boy who experienced all of the normal fears, plus hundreds of extraordinary and very real terrors, and who, on top of everything, had difficulty perceiving the world through every major sensory channel. I felt more and more angered at professionals who withheld the help he desperately needed for no other reason than that he needed it more than other children.

While Jeff was at Rosy Sky Regional Rehabilitation Hospital for the total evaluation, the psychologist there tested him and called us in for an interpretation of his findings. By this time we were not interested in what he might tell us but rather how we could use him to garner some service for Jeff. Carl and I strategized over how to handle the situation. We agreed that we would not mention the director's previous refusal to take Jeff into the cerebral palsy school at Rosy Sky. We did not want to lock horns with either her or Mrs. Braintree, who ran things around the clinic, and I think was on the committee which decided who got into the school; but we did not feel that what had happened to Jeff was fair. Jeff had never come officially before the school committee, and he had not been given a fair trial. Furthermore, people in the community, ourselves included, trusted that this program was provided for those who needed help.

We knew that Jeff had to have credé to express the urine from his bladder and to keep his urinary tract from deteriorating. The only way I could do that would be through a local school. Besides, I did not see why a private charity school in another city would take him if our own would not. Thus we hoped we could get the psychologist, Dr. Ludwig, to make a recommendation for placement, or at least formal review through the school's committee. We decided that, having once presented our need and rationale, we would not continuously beg and plead but rather, using Carl's approach, ask pertinent questions. After the psychologist had relieved himself of the "bad news" (Jeff's retardation), he told us that we were fine parents, that we had done everything possible. It was always final, as if someone had died. Carl reminded him that Jeff was still alive by presenting the premise that Jeff had improved, and that there was no reason for us to think that his growth could not continue, however slowly. I reaffirmed that for his best development he should be with other children in school where they are expected to learn.

But he did not know of any place which would take such a child. Reluctantly we told him about Newtonville, outside of Albany, but reiterated that because of Jeff's physical condition, and because *this* was his community, he should be taken at Rosy Sky. Finally the psychologist promised to talk to the director, and be back in touch with us.

After several days, I called the psychologist's office. I had learned that often enough a promise is simply a way of removing one from the premises. It was up to me to follow through. Once I had supposed that professionals who were paid to habilitate people were actually interested in that opportunity across the board. Now I realized that they had their own values and often saw their jobs very narrowly. Furthermore, they were at the mercy of in-house politics, and that sometimes was more pertinent than whatever idealism they once harbored.

The secretary informed me that the doctor was perturbed with us. He "found out" that we had already been turned down by the school. We certainly had put him in a bad predicament. In any event, we would not get our way.

"I'm sorry, but the first time I heard that, I just couldn't believe it. Ms. Houston had never laid eyes on Jeff. The second time was almost as bad. We hoped that she was capable of a little more decency. We hoped that if she were to give Jeff a fair chance, she'd change her mind." Officially, in the school's literature, they did not accept children who were not toilet trained or who were retarded. But as one board member said, it depended whose.

I tried another tack. "I'd like the courtesy of a written report on the psychologist's findings, and particularly his recommendations."

"Oh, we can't do that. We never do that," she exclaimed in genuine horror. "Why do you want it?"

"Well, I know it's not your fault, and I don't want you to take this personally, but I am angry. It's just that every time I go out with Jeff and his sister—wherever we go, to the park, to the library, to the beach—people always come over and ask questions. I don't mind; they are just curious. I didn't know anything about kids like Jeff either. But what burns me up is that they always ask why he doesn't go to Rosy Sky. I have to explain it over and over. Then they look at me in disbelief and say, 'But that's just what it's for. I *know* he can go there.' It galls me to be taken for an idiot or a ne'er-do-well—after I've tried so hard. Now, if Jeff can't go there for some good and proper reason, I'd think the doctor will not be ashamed to plunk his PhD down behind that. I just want to have it in my hip pocket to pull out in self-defense the next time I get a going-over."

"I don't know," she answered in great agitation. "I'll have to ask the doctor about it."

"Well, he understands our situation abundantly. There is no other public or private school in our county which will take Jeff. I don't see how we could send Jeff all the way to Albany, even if they would accept him. And frankly, I don't see why they should." Finally I suggested that it was incumbent upon the doctor, in common decency, to recommend some school. Additionally, I vowed that if I did not receive the written report, I would find a lawyer who agreed with me if it was the last thing I ever did.

I was surprised by my own anger, and I meant every word. It seemed to me that when professionals spoke of parents "accepting" a child's handicap, they really meant a do-nothing passivity on their part. However exalted that state appeared to them, I knew it was not for me. I was not going to let my son go on growing more contracted in his body and dull in his mind in a back bedroom, if I could help it.

When we had visited Miss Carre's class, Jeff had been withdrawn, but he showed flashes of interest and even participation during music time. I could well imagine that if he was anxious and had tuned out with me at his side in a schoolroom, how much more frightened he had been months earlier in the rehabilitation setting. He did, after all, understand that he was in a hospital, whether or not the school happened to exist there, too.

If Jeff were physically O.K. or could go to a class such as Miss Carre's for the "trainable retarded," and if he were mentally "normal" he could go to Rosy Sky. Either way, he was discriminated against for a handicap which he could not help. And that was almost too nice a way to think of it. It was a punishment. In a more humane culture, he might be given extra help. Now he was abused.

In sports, a "handicap" is a means of equalizing the game in the interests of fair play. In medicine and education, it is simply a label which allows practitioners to treat at will, according to their values and the economics of the situation. It is an acceptable excuse to shrug off responsibility with complete impunity. Even the "voluntaries," who provide special services, can do so if, when, and for whom they please. Meanwhile they provide a smoke screen which takes regular schools off the hook, creates a false sense of security in the public, and leaves parents and children without advocates. In fact, their partial-service provision added to the harrassment we encountered when we sought to take Jeff abroad in the land.

Chapter Seven
Agencies, Schools and Programs.

In due course I received the written report from the psychologist at the rehabilitation center. While it did exclude Jeff from the local cerebral palsy school, it recommended that the School for the Disabled at Newtonville might "more appropriately meet his need." We were beginning to note that whenever it was inconvenient for people to do something for Jeff, then *Jeff's* needs, not theirs, were set forth as the reason. Trying to make the best of our lost battle for local education, we knew that the recommendation which we had to initiate and insist upon might prove invaluable. I made an informal appointment with the Newtonville school to go out with Jeff. I was most anxious for Jeff to make a good impression. The decision whether or not to admit him would be made at the Albany Cerebral Palsy Center.

The School for the Disabled at Newtonville had been started as physically separate from the Albany Cerebral Palsy Center, with the center renting space from a Methodist church. In addition, the teachers were all nuns. Since I had taken courses at St. Rose College and attended various workshops which the college sponsored, I had met several women from that order. I imagined that they would be as knowledgeable as many teachers in public special education classes, perhaps more so. Women from the Jewish community worked as volunteers helping the children at lunch time. It was a truly ecumenical venture, and the school in its brief existence had already doubled in pupil size. Larger facilities would be required very shortly. Again, that would be a struggle, for contrary to the relative ease with which funds are forthcoming for normal children, quite a lot of begging is required to fill the needs of handicapped children.

I marched Jeff to the door and waited while he balanced on his walker to ring. An ample, white-robed figure met us and announced that she was Sister Gabriel. I had to laugh. Almost all of the nuns had the names of men whom I presumed were saints. Surely Sister Gabriel resembled a great lovely angel, and maybe it meant we had arrived at last.

The physical layout was similar to most schools, and there was ample supply of good perceptual- and motor-development materials in the various rooms. Some children were in the large room watching daytime television, which I felt inappropriate, but I was careful that no critical thought might pass my mind. After all, we were strangers, pilgrims, and beggars in the promised land. A piano was evident, along with the beginnings of a cooking center which they hoped to use with the children to teach meal preparation. The children who were in the day-care program apparently attended school even during the summer. They were the ones who were in wheelchairs, both spastic in body and retarded in mental development.

Just being around other children and adults might help these children. But I hoped that Jeff would get into the "academic" program. This meant that he would move from class to class every twenty minutes, much as we had in high school. Such an arrangement seemed ideally suited for Jeff's short attention span. I was told that this allowed each teacher to specialize in an area of interest and to ease her crushing burden of personal accountability when it could only become self-defeating.

The sisters thought Jeff was grand, and he hopped around eagerly. When it was time to go, he shook hands all around and waved good-bye. I was so happy that I forgot about the twenty-mile distance and other contingencies.

I was less sure of being accepted at the center itself; and of course, this was where it counted. I wondered why they should take us, when Jeff would probably ride through three counties to get there. I wondered if, since they were inundated with children needing care and education and were faced with an expensive building program, they too would now become very selective. If they were thinking along these lines, Jeff had no chance. He was not cerebral palsied but multiply handicapped. He would need to be lifted and should have the credé maneuver performed at school—a subject I dreaded to introduce. He was from another city, another county, and it was reasonable to conclude that they should take their own first. But I well knew this was the last hope for us.

I had already tried the Albany Association for Retarded Children. Several of us in the Autistic Society made efforts to find facilities for the many children who were turned away everywhere, who had "programs" that were ridiculously inadequate, or whose parents lived in constant day-to-day fear of being suspended. The grapevine had informed me that the Albany director of the Association for Retarded Children was sympathetic and that, just possibly, Jeff might be accepted there if not at Newtonville. I talked to him while we awaited an appointment at the Albany Cerebral Palsy Center. He had commiserated with me for not wanting to send Jeff so far to school.

"Damn it. We can't keep taking kids from your county. They turn away their own kids while they build swimming pools and residential summer camps instead for the few." But his resentment of having to serve out-of-towners was not why Jeff could not go there. It was for the same reason that our local Association for Retarded Children could not take him; their buildings were architecturally inaccessible. Jeff would have to go downstairs at one facility and up a full flight at the other.

The director's honesty in admitting that they could not fill the total need was unusual. Most directors pretended, at least to the public, that they never turned anyone away. If they would admit to turning away a child with these basic needs, someone else might fill the gap. Or more money for the cause might be requested. What we found instead was that everyone spent his time and energy creating a smokescreen, pretending that the problems did not exist and that anyone who accused them was a malevolent character. This made for many bitter and broken families totally without services and a public credibility gap when those families became known. The crime was not wholly in not having the facilities; it was in pretending that there was no need for them.

One of my friends in the Autistic Society, an old hand at being "exempted" from public school, told me bitterly to have faith. Jeff will look a lot better to them with $2,000 in his hip pocket." She was referring to a state law which provided up to $2,000 tuition to private schools when the child's local public school had exempted him. The effect of the law was twofold: it allowed many handicapped children to receive an education who otherwise would not, and it encouraged local public school districts to wipe their hands of any responsibility to the children.

Many districts continued to ship their children out to isolated, socially sequestered premises long after the number of these children increased to the point at which the local districts should have provided the service within neighborhood schools.

This was particularly the plight of students with mental handicaps. Many emotionally disturbed children, or children with spinal injuries, paralysis, or multiple handicaps, were not taken at all. From attending numerous meetings, we were already familiar with the regulations that required a child to be ambulatory, toilet trained, and nonviolent in order to hope for any semblance of public education, even in a segregated public unit.

Furthermore, the state sanctioned this exclusion, a blatant punishment of children for having handicaps. The education law referred to children who were too "feebleminded" to benefit from instruction. Instead of putting the burden upon teachers with bright, innovative minds, it singled out disadvantaged children to be held accountable.

The law also said that children were not permitted to attend upon instruction if facilities for their care, transportation, or instruction were not provided. Again, the school could do as it pleased, but the child's condition took the blame. If a school got generous and provided a wheelchair ramp or a resource teacher, then the child was declared to be in "proper mental and physical condition."

It is bizarre to think of spina bifida or mental retardation being miraculously "cured" by a forty-dollar ramp or a teacher with a positive attitude. Likewise, it was sickening to me, as a teacher and someone who believes in the potential of all children as well as the legitimacy of my profession, to see the state prescribe abuse of innocent children.

These kinds of statutes and policies encouraged long, expensive, and dangerous travel to socially sequestered schools run by private charities. This meant that not only did a child and his family suffer rejection and a blow to their self-esteem, but also they would be engaged in constant begging to create and maintain the same services others received as a right. Even though the state payment helped toward tuition, there was a need to raise money for the bricks and mortar for building and to maintain the expensive administrative staff these schools required, just as others do. Without the carrot of the $2,000, Jeff would have been accepted nowhere. With it, acceptance was touch and go. For the law did not mandate that these private schools had to be available or that they had to accept any given child.

When the Dr. Austin of the Albany Cerebral Palsy Center reprimanded me for trying to stop Jeff from touching the objects on his desk, I felt tremendously optimistic. Further, he seemed to agree with what I was saying about families being turned away right and left and living in tremendously stressful circumstances. It was hard just to find the time, energy, and resources to look for help. You come to the place where you cannot go on; you are emotionally leaden. You cannot pick up the telephone or write a letter one more time. If Jeff got into school, I decided to try to befriend some of the people whose predicament I understood only too well.

I left thinking that if I were successful in getting the money through the state, Jeff would be accepted for Newtonville. Jeff was nearly seven years old, and I could not help but wonder at the irony of it all. If I would decide when Julie was seven that I would not send her to school, all of the fury of the heavy well-financed bureaucracy would come down upon me. The truancy laws would be enforced to the full extent of fining me or perhaps even taking my child away or putting me in jail. In addition, I would be well publicized as some kind of nut. And here I was, using almost every day of our summer trying to get Jeff into school.

I dug out a medical evaluation which had been done when Jeff was readmitted as an emergency in Philadelphia—the only medical record we had ever been permitted to see. Jeff had been released with a fluctuant mass on his head over the top end of his shunt. Since the medical authorities disagreed, we did not know whether it was a hematoma or cerebral spinal fluid. We watched it in agony night and day for forty-eight hours before we drove six hours back to readmit him. It was a supreme irony that the report was to end up being useful. I edited and retyped it. I took it to our family doctor and waited for an hour, dividing my time between the waiting room with Julie and the car with them both.

Finally the doctor looked the report over carefully and scribbled his name on it. Then he took one of the standard little forms which I knew so well from my own childhood, the ones that certify that you are free from all communicable diseases, and scribbled his name on that. It was a wonderful feeling to witness this homey little slip which was symbolic of fresh plaid dresses, the smell of school, new teachers, and fresh beginnings pass across his desk for Jeff.

I took the psychological report down to the local public school offices, and they said they would decide whether to accept it or to have their own school psychologist make his own evaluation. This was their right, even though Jeff was to be excluded from public school. Furthermore I had to obtain an exemption form and make certain that the district sent it to the state before we could officially apply for state aid. Then I had to make application to the state. At this point it became necessary to prove that "the child could benefit." This was all in addition to finding the state-approved private school which would accept Jeff.

I made a list of very specific tasks Jeff could do, even down to being able to operate a gum-ball machine. I tried in every way to have Jeff come across as a "normal" flesh and blood little kid. To this end I enclosed a picture. I knew that Jeff was an attractive little boy, but I did not fool myself that he would always be such. All of the time we patterned I thought, "It's imperative to do everything we can now, when he's young and cute and people are willing to help." It is not a happy thought, but nonetheless it is true, that when a child becomes fully grown, or pimpled and whiskered, we do not respond in the same way.

I had heard that just lately the state was using an I.Q. of 35 as a cutoff point for additional aid, and I knew Jeff was pretty close. I also knew by now that numbers did not mean as much as personal impressions, and I wanted to do everything possible to be sure that Jeff emerged as a real live child with a head and two feet like everyone else, to whatever bureaucrat was in charge of the rubber stamp deciding his fate.

Finally we received a form telling us that the state was pleased to announce that Jeff would be approved for partial tuition for the coming school year. The form warned us that the application was good for only that year and would have to be filled out and reviewed each year; above all, the aid was contingent upon the child's progress and proof that he was benefiting.

They certainly knew how to take the joy out of getting into school. I thought bitterly of what would happen if the state ever tried to withhold education from other children or make it contingent upon their progress. I knew parents who went to pieces, and were not ashamed to admit it, when an extra day of vacation was declared for their kids. But parents of handicapped youngsters were apparently supposed to love dealing, on a day-to-day, never-ending basis, with the children whom professionals did not want to touch with a forty-foot pole.

I studied the state education law again and called our local district regarding transportation for Jeff. Gail, the secretary to our superintendent was a lifelong resident of our village and was known to both my mother and myself for many years. "Oh, you'll be taking him, won't you?" she asked, genuinely surprised that I would be calling about it. Or perhaps she was not genuinely surprised but was playing the cat-and-mouse game which wasted my days away. I hated to have a confrontation with her.

"No. There isn't any way I could do that. I've enrolled Julie in a nursery school and I'm going to be very busy with that. In any event, I just could not manage that, day in and day out. It isn't my fault that Jeff cannot have his education much closer by, and I've done everything I can think of to that end. The state law says that it is the responsibility of the school system to transport him, and I think that is fair. After all, they aren't providing him any local class as they do for other children."

It was an uncomfortable situation, and I felt and heard her shock that I would want such a child to attend school at all, but I held firm. I had heard the shock both spoken and written indelibly into the silences from many people. Even the parents of autistic children, who knew the rejection and despair which came of being summarily excluded, had said, "But you can't expect a teacher to change his diaper." At first I had been so agitated that I fought back tears of frustration and often ended up responding with some garbled, half-formed argument.

Finally I got it straightened around in my head as I washed my dishes or cooked supper: perhaps private charity should be fighting to get our children into public schools instead of building large empires increasing their vested interests and rigidity. No matter how uncomfortable or embarrassed I felt at any one given moment, I was learning to stick it out and to listen carefully to people's shock and to the things it told me about their attitudes, so that I would best know how to counter the situation when it arose again.

Although I quoted Gail the mileage to the school, she had to take a ride out there herself. She reported that it was *over* the twenty-mile limit the state designated. I agreed, and noted that my odometer turned just as I was leaving the school yard. I hoped that our district was not going to be that picayune. I reminded her that it was, according to law, the district's responsibility to find our children and keep a register of them, and to evaluate them and either provide them with education or exempt them. Thus far I had taken every initiative. I wondered how they could feel free to flaunt the law to such an extent and then hold me to the letter of the law and a tenth of a mile. I almost literally held my breath the rest of the summer.

We had a few lovely picnics and tied Jeff to trees and picnic tables so that he could get his proper standing time. He crawled into the water, put his face down daringly, and blew bubbles. When the water was getting too deep he turned toward shore. All in all I thought he used good judgment and, yes, intelligence, in his aquatic adventures. Carl and I sat back on our blanket and watched, to indulge our feelings of being just any old parents watching their regular kids and to give the children the independence we thought they could handle. Once a lady sent her little boy back to tell me that she was worried about that poor child left alone. I told her little boy gently that I was sorry it worried his mommy, but that we took great care of our children and I was watching Jeff.

Sometimes I got the feeling that if certain people had it their way, we would not be permitted to allow Jeff within their sight for fear of offending their sensibilities. I always resisted the urge to tell them that they were more deficient in more important ways than my son, and that they, frankly, offended *me*. I was learning more restraint than I had ever thought myself good for. And on top of it, I was beginning to wonder how we could effectively counter such attitudes so that everyone could feel better.

The night before school was to open, we received a call from a private transportation company and were told to have Jeff ready at 7:15 the next morning. I could not beleive it and explained that Jeff fed himself slowly and that he needed to be washed up for the night and put on the toilet every morning with time for an enema or suppository to work. His braces alone took a good fifteen minutes to put on. Of course, I had realized that we would have to speed up our leisurely summer routine, but I seriously doubted we could have Jeff ready by then. It could not be helped, he said; the bus left at 7:15

The next morning we pulled Jeff out of bed at 6:30, still stiff with sleep, and put him into his chair. When I slipped his cereal in front of him, he opened his eyes and dutifully picked up the spoon. Then I noticed him begin to shake, and I thought he was having a convulsion. He never had one before. Finally we decided it was just that he was not really awake. It was pathetic to see, and I wondered if I had the right to send him to school under these circumstances. Carl said that he thought Jeff would get used to it. I was not so sure. How many seven-year-old children would?

We both alternated working over Jeff. Neither of us had so much as a cup of coffee. I made Jeff's lunch while Carl creded him, something that was becoming harder and harder to do and which took longer and longer. Then I began scrubbing his diaper area while Carl washed his own face and shaved. Finally we got Jeff on the toilet, and when he still had not gone in the alloted time, I had to put on a plastic glove and fish the suppository out of his rectum so that it would not work later and cause him to have a bowel movement at school. That, of course, would be the last straw. Finally, we both worked diapering and getting Jeff's braces on. At last he was ready—a little late, but the bus was not there yet. I knew that we would gain a little on the routine, but I also knew that we would lose the first flush of excitement and adrenalin driving us that first morning.

I stood with Jeff at the picture window, watching and waiting for the school bus. Julie stood waiting too, sensing that this was an exciting time. She would start nursery school the following week, and she was enthralled with the idea of a school bus coming for Jeff. I tried to explain that it would be little, not big like the ones the neighborhood children went on. I pointed out Scott Silva getting on the bus, and later the younger children leaving for elementary school, and still the bus did not come for Jeff. He stood there proud and anxious, peering down the road.

The sun was up now and it was fully light. I felt better, and it seemed years ago, in a bad dream, that we had pulled Jeff from his bed in the darkness. Now he looked full of health and energy. Maybe it would be all right at that. Jeff was swinging back and forth on his walker by lifting himself into the air on his arms and swinging his legs through the air several times, singing "hup, two, three, four" and something from Dr. Doolittle.

I began to worry. We had talked to him about going to school, how the bus would come and take him there and bring him back again at night. It did not seem to occur to him to be frightened, and I thought that his remoteness sometimes had advantages. A long time before he had heard a story about "Raymie" on his talking book records, and he kept repeating, "Raymie was seven years old. He didn't go to school yet," and I wondered if he wanted to go.

At about twenty after eight Carl called to see how we made out. I could hear the disappointment in his voice too, but he figured this was probably par for the first day, with all the new schedules and routes. Julie had not had a bite to eat because I had been expecting the bus, momentarily, for over an hour. Finally, at nine I decided to take Jeff myself and almost simultaneously started getting Julie something to eat and packing up to leave.

The phone rang and a woman introduced herself as the secretary of our school district's psychologist. She wanted some information on Jeff and the school we had in mind for him, just as casual as anything. I looked at Jeff still standing by the window, marching to his own little tune, and stretched the telephone cord so that I could stand behind him in case he might fall. He was such a sweet little kid and I was sick to death of having him treated as an undesirable element.

"Wait, please," I interrupted her. "Are you trying to say the school bus is not coming this morning at all?"

"Why, no, Mrs. Pieper," she replied in cool amazement. "We don't know anything about this school. We've never even heard of it. Why, we can't just approve a private school for your son without proper investigation."

I was almost speechless with rage. For all of their dereliction of responsibility, the insult to my child and the inconvenience and hassle for me, no apology, just the never-changing smugness and irritability which came of trying to do us a "favor" they obviously felt unjustified.

"Look," I said close to tears. "Think what you will. I'm going to hang up on you and take my son to school. He's been standing here at the window for two hours, waiting for his school bus. You had weeks, months, and years to call me. I'll take him to school because he deserves that much consideration, and then I'll talk to you." I hung up.

By now I had heard all sorts of exasperating stories of terrible struggles by parents to get their children with special problems into school. One mother told us that she had finally called the superintendent's office and said that she would not hang up until she received satisfaction, and that her friends would help tie up their phones indefinitely if need be. I had heard of sit-ins, but it was the first time I had heard of a phone-in.

One man who had a multiply handicapped son told the superintendent that if there was no room for his son, there was no room for his other children either, and he was removing them from school until his son was taken off the waiting list; they were tired of waiting. He affirmed that the district opened a new class in a hurry. Although the district had maintained that there were not enough children to justify the class, it was filled before its first meeting! Soon after, the district was seeking federal funds for a new wing to accommodate all the disabled children who appeared out of nowhere. And, of course, I noted that the officials were taking public bows for their zeal.

Later I called the psychologist's office and the matter was resolved. By the next week, we had a "bus." It swung crazily into the yard and stopped abruptly. It was not yellow; it had no sign; it had no special lights. In fact there was nothing to indicate that it was anything more than a shoddy old station wagon with well-worn tires and plenty of rust and dirt. The young girl who got out wore her bleached blonde hair in a highly teased style hanging in puffs and snarls nearly to her waist. She wore a tight sweater and pants, both shabby and full of catches and pulls, and chewed a great wad of gum. I noted that there were no seat belts and decided to put Jeff in the back of the wagon alongside another little girl who had been picked up well before seven.

I told her about the arrangement we had to tie Jeff to the car frame and tried to explain that if the car stopped fast, the children would keep going and get hurt pretty badly. She did not have time to let me tie him down, and I surrendered him with misgivings, even though she assured me that she "wouldn't stop fast." She had four kids of her own. She loved these kids, she said repeatedly. The car had shifted into high before she reached the end of our lot, and she sped down the road to make up for lost time. That night she brought Jeff home at five o'clock, tired and filthy and covered with cookie crumbs from the bag of cookies she had given him.

When I objected to the time, she responded, "Hey, what do you care. I'm a free baby-sitter."

"Berni," I said with as much restraint as I could, "if I were looking for a free baby-sitter I'd have put Jeff in an institution long ago. This poor kid has urinary problems and we have to express the urine from his bladder at certain times. He needs fluids, and he can only tolerate his braces for a few hours. Pressure sores can be dangerous for him. I mean, look at him, he's been up since six-thirty."

"Hey, I've been up since five, and I worked last night, I travel three hundred miles a day with my route. I didn't even have lunch."

I asked her in and made a cup of tea for all of us while I changed Jeff. He gulped the tea-milk like he had never had a drink before. Next I put Jeff into the standing table, hung up his sweater, cleaned out his lunch box, and started dinner. I began to feel more and more uneasy as Berni told me that her four children were in foster homes. She was in no hurry to go back to her rented room. Her husband was running with a motorcycle gang somewhere, but he was no great loss—a transvestite, she said. I felt naive and guilty at my blessings as she spoke of having had a baby born with "a veil" across its face. It seemed that she had predicted from the moment it was born that it would die, and eventually it had. I felt sorry for her, but when I heard that she worked four nights a week as a barmaid, I began to worry about Jeff even more.

I knew that in addition to traveling so many miles a day, she picked up children in three counties, perhaps four, and hit a lot of city traffic with a tight schedule to keep. When I thought of it in terms of our trips to Philadelphia and the great weariness which overcame us, I was ill to think of her routine, day in and day out. She assured me that she had driven big trucks and liked driving. Also, she loved the kids. She would not let anything happen to them.

A couple of days later, she was greatly upset because she had stopped short and cut Desiree's head quite badly. I tried to calm myself, but there was a rising hysteria within me. I wrote a long letter to the editor of our newspaper about the need for a school for multipy handicapped children locally, so that they would not need to be dragged from their beds asleep and travel such long, dangerous hours with the sometimes disreputable companies who present "low bid." On the same morning my letter appeared, Berni showed up with her arm in a sling and her face badly bruised and swollen. She said she had been "in an accident."

On the front page of the local section of our morning paper, back-to-back with my letter, was a story headlined "Police Chase Ends in Arrest of Woman Driver." It described a wild chase through the city which at times involved four police cars. The woman, who was Berni, had for some reason smashed the windows and headlights of her own car, which was parked outside a tavern. The police followed and lost her but were called again when she threatened to break the window of a second tavern. Once again she eluded them. Finally she was arrested at four-thirty in the morning and charged with reckless driving and resisting arrest. The story noted that she drove a school bus as her occupation. This was only the beginning of the transportation problem we were to face as parents of a child who is not valued and for whom education is not provided locally on the same basis as for other children.

Of course, one of our ongoing personal concerns was money, and this indirectly led me to look at the whole education issue in a much broader way. When Jeff was hospitalized the following fall, we realized that there was no mechanism to guarantee that we would not slip into bankruptcy. We had pressured to be included in the county-run program for crippled children and were put on "state aid." This meant that the family court ordered us to pay $50 every month as our share of Jeff's medical care. This was for one child and for "projected expenses" only, and was nearly 10 percent of Earl's take-home pay. It covered the initial evaluation at Rosy Sky, an orthopedic surgical procedure, initial therapy, an intravenous pyelogram study, and a wheelchair. The rest—insurance premiums, bladder surgery, shunt surgery, out-of-town travel, and braces which were not anticipated—were not taken into account. One month while on the program we ended up paying over $300 of our own for current medical expenses for Jeff alone. Such is the nature of our bureaucratic response to human need.

We had $60 left to our names and determined that the most sensible thing to do would be to move nearer Philadelphia. We looked at four states and found General Electric plants where conceivably Carl might find employment. Previously he had turned down an exciting job offer in California because the medical insurance benefits were not good and a preexisting condition could not be covered. Thus, Jeff's condition affected every aspect of our lives.

I started by querying seventeen school districts, numerous private charity agencies, and all of the state-level education departments. For several months all of my time was spent in this search, following down every conceivable lead. One of the ironies was, of course, that the cerebral palsy school near Dr. Spitz's clinic, directed by Dr. Downing himself, would not take Jeff. He was not one of their shining stars, and when it came down to practical matters like a right to education, they elected to serve only those who held more promise than Jeff.

Essentially everywhere it was the same story as locally. In fact, I understood that Jeff was "lucky to have anything at all," as the local cerebral palsy director had put it. I could again read the awe which some people felt that I would seriously be searching for services for a child who was so "severely involved," as they termed it. In some cases we received communications saying that the state had classes for emotionally disturbed, physically handicapped, learning impaired, retarded, and five or six other labels, but there would be nothing for a child such as ours.

Sometimes I would try to "educate" them both on clinical issues and in regard to philosophy and rights. Endlessly I pointed out that they routinely provide all manner of "peripheral" supports such as hot-lunch program, band uniforms, football coaches, athletic equipment, transportation to sporting events, instrumental lessons, and the like. While I felt that was good, I could not see much difference in providing ramps or even therapy aides so that other children could have the basics to which I felt they were entitled.

One principal near Philadelphia seemed hopeful, but after relaying a few questions to the special education supervisor, he informed me that it would not work. Then he said, "You're a young girl yet. Why don't you put the child in an institution where he could be well cared for?"

I informed him stiffly that the two were almost mutually incompatible. I had seen institutions; he had not. I was sure he would not put one of *his* own children there.

"Still, you owe something to your husband and to yourself," he went on. "You're still a young woman."

Walking around the strange town, I thought about that. Things were not always good between Carl and me. But I could not be any better wife to Carl if I did such a thing to our child.

I had, in desperation, suggested it once to Carl, and he had cried. We did not want that. I knew full well that we were both giving up a lot to "keep Jeff." It has always struck us as bizarre that only such radical alternatives were available: a life of martyrdom or giving up on your child.

But within this I found a purposeful life; perhaps because of this. My resentment, bitterness, and anger were coming together to demand new alternatives—not only for myself but for others. I knew I would never have a new car or perhaps even reliable transportation. Technically, that should not happen to people who "work hard." It was just one more expectation blasted to pieces because, frankly, it is one of the many cultural lies we tell ourselves. But I knew too that I would never have to confront who I am and why I am here in quite the same ways which many more fortunate people do.

Almost every time I went out with Jeff I came back with a new name and address of someone with a child "like" Jeff. Almost always the friend, neighbor, or relative would approach me with the information but decline to be mentioned in any ensuing transactions. Unanimously they seemed discomforted at the family's predicament and the fact that nothing was being done to help the child. This often came out in the form of blaming the mother. "She's not like you; she doesn't care."

I knew what it was like to be beaten into the ground, to feel so rejected and full of despair that I did not want to get out of bed. I knew that people who did not have typewriters or college educations often felt that they could not write letters, and that people who did not have a second car, as we now did, could not attend hearings. People who had several other children often had no time, energy, or money to go to the lengths I did. Besides, when society tells you long enough and hard enough that you are guilty, that you have burdened them and that you are too much trouble, you may take your tail between your legs and slink away to an existence of quiet martyrdom.

I began to feel a tremendous need to reach out to these people and to share not only our frustrations but our strategies for success, or at least to analyze our failures and to learn together. I made up a list of all of the steps required to get a child into school, a brief summary of the New York State education law, and the informal tips I had learned about dealing with administrators. The list emphasized asking pointed questions and keeping notes. These went out to everyone I heard of. The names and addresses of their legislative representatives were enclosed with the idea that legislators should be made to understand the situations which prevailed.

Most people called, and we spent hours on the phone. Sometimes I wrote letters for people, working from what they told me. These I typed, addressed, and stamped so that they could either be signed and sent on or considered as prototypes for similar efforts.

At times I did informal educational evaluations with their children, telling parents what they would be likely to encounter in testing, what some of the activities were called, and why they were felt to be important. Sometimes brothers and sisters would stare in amazement, watching carefully. At times the other children beamed with pride or exclaimed, "I didn't think he could do that."

I wrote to legislators and administrators alike, protesting policies and asking that they be changed. Sometimes I became disenchanted with the very mechanism I thought was a godsend before looking at the overall picture. For example, after I heard adults who had been segregated a great part of their lives in school testify as to the damaging psychological and practical effects, I began to fight financial incentives to building private charity schools or segregated settings. When this happened, I went back to legislators explaining why my position had changed and asking that others reconsider. It became essential to look to people who were the real experts, those who had disabilities, to guide our efforts. Likewise every "solution" or idea had to be tested against the long-range interests of a whole class rather than one individual.

Thus I learned something that corporate planners have known for years: to be highly skeptical of individual, shortrange relief. For example, every time we got a child into a private school, we realized that we had filled up a space which some other child could not have. Then, another child would be swept under the carpet, put on a waiting list, or shipped out of his community. Finally, when it seemed expedient, depending upon whether a director liked swimming pools, clinics, or schools best, an addition might be built. This in turn would tend to underwrite the segregated system by announcing to the public sector: *You* don't have to do it. This is where "they" belong.

Since I had begun to think of education in terms of civil rights, I dug up the *Brown v. Topeka Board of Education* decision. This tended to reinforce my feelings that exclusion and segregation are not only cruel; they are also unconstitutional. When I read *Throw Away Children* by Lisa Richette, I was impressed with her compassion. More importantly, she was a lawyer.

I wrote to her outlining my concerns and presenting the idea that a legal suit should ensue to clarify that the Brown decision meant our children too. She never replied, but when a landmark right-to-education suit arose in Philadelphia, I fantasized that perhaps old Lisa had mentioned the possibility over cocktails to some of her legal cronies. Or, perhaps my prodding and chastising around Philadelphia began to stir people to think and act in new ways. At least I felt tremendously heartened to have a Philadelphia lawyer out for our children.

A previous effort left me with no cause for optimism. I had written to several major voluntary and parent groups asking that they bring such a right-to-education suit and that they form a coalition specifically to caucus and develop strategies for change on a systematic basis. The executive director of United Cerebral Palsy replied that they did not "believe in taxpayer suits of the kind you recommend." He went on to note legislative achievement and existing cooperation with other groups. This seemed about as effective as the "public education" which many administrators relied upon as the answer. Although these were necessary, I felt they were needlessly slow and not as innovative as they ought to be.

Furthermore, validating our children's rights and pushing the parameters of the system with legal action seemed essential. In the education of children, behavior modification was highly touted. Why should it not be used on systems which were almost impervious to change by other means? Apparently legal action was acceptable for corporations and high-level management, but when promulgated on behalf of ordinary people needing help, it was tantamount to barroom brawling.

Finally, I filed a complaint with the attorney general as the best an ordinary citizen could manage without money or legal help. The National Society for Autistic Children followed suit. The former bankers, educators, health-industry people, and lifelong bureaucrats saw things differently; neither did they have children with disabilities or spend twenty hours a day thinking about change. What they did was to effectively control some of the organizations which could have been our most powerful advocates.

Chapter Eight

Institutions

Someone from the Albany Cerebral Palsy Center had called us shortly after the opening of school. They had planned a tour of the state school about ninety miles from us for the parents of some of the most severely handicapped children. We thought this an excellent opportunity to see the inside of an institution and hoped somehow to put our minds at ease about Jeff's fate after our deaths. It was an extraordinary endeavor to arrange to get away for the several hours which traveling and the tour would entail.

There are not words to explain the terrible impact this tour had upon me. As we walked through the halls and had our lunch, we talked to other parents about the neglect and condescension which breed this kind of "alternative." Everyone had similar stories to tell about the professionals, usually doctors, often the only people to see our children in their early, formative years on a regular basis and therefore our only hope for binding our children to the community. Yet they neglect us and turn us away. Over and over we expressed to each other that it did not take a college education to predict that any child left like this would turn out retarded in development. One woman told me how Dr. Ludwig had sealed her child's fate in less than ten minutes. She thought she had just lit up her cigarette, when he reappeared so quickly that she had to check the ashtray to see if she had had a lapse of memory and was chain-smoking.

Ironically, a few years later, a mother called me in regard to services for her brain-injured daughter. It turned out that her sister had been secretary to Dr. Ludwig for many years, probably the one I had threatened with a lawyer. These kinds of kids "upset him too much," it seemed, and sometimes the secretary had to give them the tests herself! I decided that it was time we stopped talking to ourselves about these dreadful things and started talking to our legislators. Surely they would not permit such horrors if they knew what was really going on.

We saw no one brutalized in any physical sense while we were there, although we were well aware that we did not see the back wards. We looked at the massive wards of tiny old-fashioned, white painted cribs lined row upon row with barely the prescribed distance between them. We realized that this was where Jeff would lay for the rest of his life if he were institutionalized. There were no wheelchairs and no place to go if somehow someone could get dressed and into a chair. There were no toys. The cribs were too small for a great many of the occupants, but the children could fit by virtue of the fact that their limbs were permanently contracted—such as happens to prisoners of war in tiger cages. In this drawn-up, fetal position they could be contained by the small cribs. They were fed enough to maintain life. Probably because of the lack of exercise and hurried feeding schedules they did not grow very much, and there was no reason to wish that they should. I looked at and talked to several children lying there, and their eyes were sometimes alert, and I ached inside because I knew that something should be done for them. Many of the things which would help them did not cost a great deal of money but required a different outlook. The institution would have to cease to be a holding bin, and people could not be considered waste or excess.

I was filled with pain, rage, and indignation, for I saw the affront to those children as an affont to all people, to human dignity, to a whole species whom, as the psalmist said, God Himself made a little lower than angels. Certainly, to allow this for some of our children devalued all of them. It was perhaps in a strange way a measure of how little we think of ourselves. Surely it is a judgment on us more than it is a reflection on them, for they are not there of their own choosing. Long after, when a mother asked me in anguish, "Why do we do this to our children in the United States?" I replied cynically, "Because we are rich enough. We can afford to."

Because of the devastating effect of this visit, I drew up a list of recommendations in every area, from early screening and treatment to things which I felt fed into the reasons people caved in and placed children in these human storage bins to await their deaths. It was a very complex area and I felt that Carl and I, because of all we'd been through had a tremendous insight into the cause-and-effect relationship.

One of the most shocking and, I thought, potentially useful arguments was the high cost of institutionalizing a child. In New York State today it costs between $20,000 to $30,000 per year for residential care at large institutions.
The amount of *direct service* to each patient was less than is afforded most animals in a well-kept zoo. A lot of the cost was for brick and mortar maintenance, ground maintenance, heating, and administrative staff. It was an enormously expensive proposition in which it seemed that nobody won. It would have been a lot smarter to give easement and incentive measures to families and foster families to run small group homes and to build architecturally accessible low-income housing mixed in with other housing units. Finally I realized that the legislature does nothing without a study commission first, even when they already know what is wrong. A report is subsequently filed and becomes part of the theoretical expertise of the department running the institutions, whose top people knew it all along. Then, most often it is forgotten. Apparently we do not really want to change.

Some people say the Europeans are more humane than we are, I say that they have a heritage of frugality and that they have stumbled on their humanity unawares, taking the most sensible, economically sound course of action. We are just as humane basically, just as decent; but we are perhaps too rich and perhaps too "good." We want to do *special* instead of typical things. The final irony is that we, instead of listening to parents and doing what is natural and decent, are now spending even more money sending "experts" to these countries to find out what they are doing! It could not happen anywhere else.

After the visit, I was still so dazed that I stood absentmindedly making peanut butter sandwiches while I had a meat loaf in the oven for supper. A man from the Albany Cerbral Palsy Center called and wondered how we liked the visit; just as if we had been to a tea party with the queen. He suggested that we should think about admitting Jeff and recalled the wonderful talking typewriter, the thousands of dollars worth of technology, and thousands of dollars worth of staff. All I could think was that our Jeff would be in one of those chipped white cribs all day and all night. And I knew that the man was not really caring that I could not take care of Jeff forever, but rather that he was too much trouble at the school. I just kept saying that I could not do that, expressing how grateful we were to have help, to have Jeff in school at last. Later it hit me that he was perhaps telling me that they would not continue Jeff at school, but I had not understood. Unwittingly I had embarrassed him into a stay of execution.

My grandmother had had a stroke before we'd begun Jeff's patterning. When we had all gathered in the little bungalow, it was in some aspects like the dreadful hovering of vultures at an impending death. Grandma was put to bed, the doctor was called, and everyone prepared to accept the inevitable. Many of the specifics are mercifully gone from my head. I sat for hours while relatives came and went and verbally disposed of the house and contents in any number of different ways, delicately cautious of having any disagreement get out of hand while Grandma was still alive. Traditionally no deposition was assigned to Grandpa, who was now wetting himself at times and probably would not know how to make a cup of instant coffee toward his own sustenance.

I sat with Grandma and watched her with a sort of fatal fascination. The whole side of her face lay limp, and when she made an effort to move or speak, the effect was grotesque. Spittle formed at her lips constantly, and she was drooling. The saliva spilled out from the side of her mouth. I wiped at her mouth and tried to think what I could do to make her comfortable. A lot of things went through my mind. I felt ill at ease, even embarrassed at seeing my grandmother like this. I wondered why our pain is so often translated into rejection or even revulsion. I had seen nurses and aides treat nonverbal patients in an almost brutal way, never trying to hide their disgust and impatience. I loved my grandmother very much. I thought she was still inside of this mocking body. I thought of how I would feel if I were laying there with half of my face falling away. She made efforts to control the saliva, to swallow, and these seemed to follow my wiping her mouth. I supposed she did not know that she was drooling until I wiped. It was hard to imagine what she knew or what she was thinking.

My aunt particularly was in and out, issuing orders. I felt an intruder, even though Grandmother and I were very close. Grandpa, too, sat apart. He was like some well-meaning but slightly retarded member of the family who is tolerated with varying degrees of patience but who is clearly in the way of the real business at hand; which was? Well, dying, I guess. I was timid to touch Grandma for I knew they would be quick to blame me if "something should happen." On the other hand, all of their conversation was predicted upon Grandma's dying. There was no provision for sharing responsibility and work should she live.

The more I studied her, the more I realized that she was not dying. She swallowed more distinctly. I held her hand, so heavy in its limpness, and rubbed her cold arm. I talked to her, hoping not to be overheard. "The doctor says you probably had a stroke. But you're all right now. It's over with now. You'll be all right, Grandma."

"What's the matter with you, telling her that! Telling her what's the matter with her!" I knew my aunt left out "you goddamn fool," which usually rode cadence whenever she addressed my grandfather lately. I appreciated that, for I was timid to defy her.

Somewhere along I had toyed with the idea of getting Jeff for Grandma. I left, telling Grandma where I was going and that I would bring Jeff back. Sure enough, as soon as she saw him, she started thrashing around, tangling her sheets, trying to sit up. We tried to calm her, but she made a greater and greater effort to speak. Finally I recognized the summons which I had heard so many times before over the years, often with irksome annoyance. Now tears of joy filled my eyes at the homely injunction, "Go get him something to eat." We gave Jeff a cookie so that Grandma could rest and still have the pleasure of seeing Jeff devour food.

It was a pleasure to watch him, as his face often expressed a singleminded joy. We were very strict about sweets because we realized the problem any dentist would have even getting his mouth open, given Jeff's alarm regarding doctors. Grandma had been the brunt of my righteous indignation, but she continually smuggled a bag of jelly beans along to sneak to Jeff at every opportunity. He knew where she kept them too, and always headed for the proper cupboard as soon as I put him on the floor. He loved Grandma and her goodies.

He was not afraid, but regarded her with interest while she tried to talk to him. I could understand more and more of the slow, thick speech. Finally she would not be still, and it was evident that she was getting up. It would have required more trauma to force her down than to let her "exert" herself to get up. There was nothing we could do but help. Even my aunt was excited and, while issuing all manner of epitaphs concerning Grandma's impatience and stubbornness, prepared to help.

Perhaps Grandma was surprised to feel only one leg under her after eighty-odd years of walking on two, but she did not repent her mission. Can you imagine three people pulling, holding, and hauling an old lady with no balance, and no one sure where she was headed? By the time we had settled Grandma in the living room, her speech was greatly improved. It was almost as if the frustration and size of the struggle had elicited not only the need but also the facility for communication.

Within a few days of her stroke, Grandma was up and around, and I would find her laboriously practicing her writing like a diligent third grader. Endless lists of sugar, coffee, milk, and bread would issue forth with touching effort. Her name would appear in great, rounded letters connected only here and there.

"Chicken-scratchin'," Grandpa would say. "Always scratchin' away like an old chicken," he would repeat with irritable pride.

There was a long period of good recovery, and Grandma could do most of her own work, complaining that Grandpa was getting awful "feeble." But the situation in general was deteriorating. We offered to buy a used washing machine and have Carl plumb it in on the enclosed back room behind their kitchen. This would be a tremendous improvement over the old wringer machine in the basement. My aunt would have no part of it, and seemed to prefer running to the laundromat. My uncle would not even answer his phone anymore, let alone visit, owing to misunderstandings with my aunt. It was a tyrannical situation and I felt very sorry for my grandparents, who were essentially at the mercy of my aunt and trapped in their own house. My aunt in turn was at the mercy of the stress from struggling to do too much. The situation had become so difficult that we were all trapped by its cruelty.

There were no services such as Meals on Wheels of which my grandparents could avail themselves. The visiting nurses services were so expensive per visit that my aunt said that they could not afford it, and besides she ended up with all the towels and sheets to wash anyway, and that was the worst part. She could not find anyone to come in to help with general chores for a price my grandparents could afford. Of course, they had equity in their house, but they did not want to move. The help-wanted columns attested to other elderly and disabled people in the same cruel situation. We thought and thought. If only there were some way that the equity in their house could be insured and signed over to some agency which would provide some daily care within their home. Apparently their only recourse under the present system was to deteriorate to such a state that they would need total care and then enter a nursing home or county facility, at tremendous cost, to deteriorate further until they could die.

Finally Grandmother became completely dependent upon a wheelchair from a subsequent stroke, and Grandpa was literally reduced to half walking, half crawling, to the bathroom and kitchen. His accidents were more and more frequent, and the once immaculate bungalow began to reek with the smell of urine and Lysol.

Sick at heart and physically weakened from malnutrition, my grandparents were literally taken from their home. Even Grandma, who had agreed to go, did not want to and protested and cried at the last minute. Grandpa rallied with more vigor and strength than I had seen in years, and his still-thick muscles stood taut against his smooth, thin skin. I wished with all my heart that there was some way he could win that awful struggle. It was just too terrible that something like this could ever happen. Whenever I thought of it, I did not want to get old. And then I knew that it happened every day, even to young people, to paralyzed or retarded people whose families could not keep up anymore. There were, I knew, forty-year-old housewives and fourteen-year-old boys and thirty-year-old engineering graduates sitting in nursing homes mainly because they were paralyzed and needed more help than they could manage by themselves. It was something I had to just put from my mind because it sickened me so.

In the beginning I tried to visit every day until they became accustomed to the place. Then my visits were two and three times a week. It was very difficult as all this occurred while we were patterning, and sometimes I had only twenty minutes until visiting hours were over at night; but I felt a part of me lay there alone, and I had to go. I always felt better to see them, if only briefly. The most awful part of the whole awful business to me was not the barren rooms where there was place for no cherished memento, but the fact that Grandma and Grandpa were separated.

The nurses regarded me as a medical illiterate and tolerated me with a mixture of sympathy and impatience. Of course, they would take Grandmother over to visit Grandpa if they had time. They did not have time. And they could not lift her. And the aides were busy too. No, I would not be able to do it myself; absolutely no. No, I would not be able to hire someone; against regulations—and besides, why didn't I take care of them if I had that kind of money! In the year Grandma and Grandpa stayed there, they only saw each other once, and then in the presence of other people waiting impatiently to return Grandma to her room. To me this was obscene.

It was hard to see Grandma and Grandpa like this. I think that is why everyone stayed away. Who knows what to say to people who were once virile and strong and who provided nurture and comfort as well as criticism and reprisals? Who knows how to say good-bye day after day to a life that is already gone and not able to be mourned?

Grandma had a bad spell even before Jeff's shunt surgery and our many trips to Philadelphia in the summer of 1967. I had not been able to see her very much for a couple of weeks. In the end she told me that she just could not die until she knew how her little boy was. I was deeply touched. I was able to tell her that the Lord was watching over him, that I believed He really held Jeff in his care.

When Jeff came home, I took him to visit. Grandma rallied in good spirits to express her relief and thanksgiving. We had only a few visits after that, for she slipped, mercifully, into a coma. By now her leg had become gangrenous and was literally rotting off, while she lay there suffering the pain with nothing to take her mind off of it except her roommate's soft drawl, "Run fetch that chicken, honey. That's a good girl. Yessem."

It must have been a unique kind of mental horror. Even the smell of rotting flesh was awful, and there was no way to mask it. Finally she was moved to a private room with an electric deodorizer humming softly. I sat with her and held her cold, unresponsive hand and watched her puff her cheeks out and blow every breath out in a long, tired effort. I read her favorite passages from the Bible and wondered if she could know or understand or feel anything at all, if she was frightened or alone anywhere within her soul or mind. I knew she would die very soon, and it seemed extraordinary not to be able to share this momentous occasion. I almost wished she would die as I held her hand, and wondered if that was wrong.

When the nurse called in the morning to say that Grandma had "passed away," I was uncomprehending. Then I thought that I should do something, and I said I would be right out. She said, "There's no need for that." Grandma's remains were already at the undertakers. They had all that information on file already she explained, proudly impatient. All of her belongings had been removed from the room, and if we wanted anything . . .

"How did she die?" I asked, struggling to maintain some contact with my grandmother.

"She just passed away peacefully." Her voice sounded like the "satisfactory" the switchboard operators give out on hospital patients. Once we had accepted that description literally and rode six hours to take Jeff out, only to find that he was on the critical list. I would never know how Grandma died. It was senseless to ask. It was finally over. The nurse cautioned me not to tell my grandfather; it might jeopardize his condition.

I thought of all of the nights I had run back and forth through the halls reeking with urine and disinfectant, past the great, bony bodies staring with hollow eyes from dimly lit rooms, to answer the question "How is Jule?" or "How is Herman?" as honestly and wisely as possible. It seemed a cruel joke that a marriage which had survived hundreds of quarrels and kindnesses, the birth and death of several children, the Depression, which had spanned the advent of steamboats and towpaths as well as the automobile and space ships, a marriage and a caring that had lasted almost sixty years, could end like this. How could I go to my grandfather, having buried his wife, and not tell him?

If I did tell him, I would have to openly defy the nurses, for Grandpa was hard of hearing. Sometimes I would try to say as little as possible to save the embarrassment of yelling. Once when he questioned me, and then did not respond to my answer, I asked loudly, "Do you hear me?"

A great, bawdy chorus arose from the adjacent room. "Yes, we hear you. *Everybody* hears you." Loud gaffaws and half-stiffled titters emitted from the nurses and aids who gaggled in the tiny lounge. It embarrassed and angered me. I could not remember seeing another visitor in Grampa's wing in the months I went. And here all of these people sat in comradery—young, comfortable, and secure—ridiculing my puny attempt to communicate with a lonely old man.

Fearing I would get caught and perhaps banned entirely, I postponed my visits until I thought I might deceive him. I still did not know what to do. I did not tell him, but I think he knew. Once I even lied and told him Grandma was very sick. I felt I must tell him. A nurse warned me again. I was angry and frustrated and confused. In the end he knew.

At Christmas time I felt embarrassed to see that mine was the only card on his cold, broad windowsill. It was so unfair that a man who loved grass and flowers and the earth so much should end up in a bleak, sallow room barren of any sign of family, friend, or past glory, without so much as a green bough. If only I had brought something green, something that was once alive. When he thanked me for that card, that pathetic, miserable, hastily addressed card, I thought I would burst from grief. All of the pent-up sorrow of a lifetime was within me the way it was the night my father died. In the car that night, on the way home, I cried—a silent, aching cry for all those people we store away because we are afraid to look at them, and into ourselves, to see our frailities and what we may become and what we already are.

On January 4 of 1968 we made one of our frequent journeys to Dr. Spitz in Philadelphia. When we returned, the county home had been closed because of a flu epidemic. I was never to see Grandpa again. Before the month was out, he too had died, and we buried him in the bleak and frozen ground.

Among the many notes I keep, I found this poem which I had written when I first noticed how my grandfather had slowed down. As a young child, riding the bus with my parents, I had craned to see him from the window as he bent to his labor in the village park. I was proud of the labor and of the beauty he created as a gardener. I find that I cannot leave him, even in a book, alone or in barren ground for that is not how I would have him remembered.

On Coming Out at Ninety

Each year he comes out, like a perennial.
This year he came more slowly than before,
Looking strangely like an aimless marionette,
Gently bobbing in time to a nonexistent tune,
His body listing from one side to the other,
With the soft and rhythmic pat, pat, pat,
Of first one foot and then the other.
Looking for all the world like a string-suspended doll,
Dancing in place,
At last he gained a few paces.

And it was not aimlessness that brought him out.
It was a well-precedented and wholly predictable
  pilgrimage
He went on this time of year.
Before the snow was completely melted,
He had said that the dandelions would have to
Come out from his lawn.
And so the sun beat down upon his old white head,
Still failing for all its warmth,
To take the gathering chill out of his half-numb feet,
His hands are busy wrestling weedling root by root,
From his precious little plot of grass and dirt.

The skin hangs loose and silken on his brown hands,
I wonder that the sterile winter has not claimed
  their tan,
As they tremble in a perfect rhythm, moving
  precisely,
Through the honored movements of nearly a
  hundred springs,
Digging, pulling, shaking and scraping,
The earth from tangled roots.

It comes to me,
All of a sudden,
That he could be spared so much of the grueling
  tedium,
With modern methods.
But the thought flees before it passes my lips,
Chased off by a sudden, almost strickening fear,
That the weed killer might destroy more than his
dandelions,
And he might not come out at all again.

And so I am content as on many warm, spring

days before,
To sit and dig dandelions with him,
Listening ever more patiently to his gentle chides,
"You have to get the whole root or it's no good."
I muse that perhaps I dishonor science
and my degree,
To sit on this damp lawn
In full view of everyone
And dawdle in cool dirt,
And yet I love this old man
Who fulfills part of the promise of spring to me,
When he comes out each year.

Why do we, when people need extra help, douse them with our modern weed killers? With white uniforms and Lysol and ridicule and separation? Why do we call our extreme alternatives "homes" when there is no room for personal belongings, a picture on the wall, or friends to come and go at will? Why do we call them schools, when there is technology but nc growth? Why do we say that "their" needs are being taken care of when it is our needs which are being filled? Our need not to see vulnerability or share responsibility? Our need for jobs as caretakers, as builders of buildings, as financiers making profit on bonds, as a medical industry creating sickness of soul and controlling standards and staffing in ever more areas of people's lives? And why do we call those places by euphemisms if not to continue our own deception?

Could we not feel better about our own ultimate fates if we did not create and prey upon the dependency of others? Can we not offer, and demand, sensible alternatives to total "care" and total neglect which are almost indistinguishable except for the settings?

Chapter Nine

Charity

A society such as ours, which creates superstars and presidents out of other peoples' advertising skill, ought not take too seriously those administrators who cry that the public will not accept "them" —especially when lackluster little countries which have never put a man on the moon, have no monopoly on morality, and view our Madison Avenue and Hollywood products with awe, can manage more creative alternatives and "acceptance." Work stations in regular industry and buddy systems for people who have special problems astound our experts who travel abroad. Here they are used to the dreariness of sheltered workshops, where row upon row of labeled people sit stapling, sorting, and packing like inmates of concentration camps or the Deltas of the brave new world. Here they are used to segregated settings of every sort with an army of human-service managers directing the lives of people who have no power.

One begins to suspect that there is something other than poor attitudes and the lack of ingenuity or goodwill involved. One begins to wonder if these are not handy excuses for building and supporting segregating institutions. In 1834 England passed a bill which created a model of administrative machinery and the whole class of civil servants interested in the control of impoverished people. The workhouses were so horrible that people feared them as an alternative to being exploited and patronized in the community. For although their toil might be equal in each place, in the workhouse the inmates had no control of their own lives, and they were banished even in death by burial in special plots. This act was hated by the people, but nevertheless provided the model for services to this day. The irony is that this bureaucratic answer was supposed to solve the problem of the hit-and-miss charity of the community, which was perceived to be an extension of class exploitation.

In one of Dickens's Books we find Betty Higdins, who, living in fear of the workhouse, finally gives her grandchild to rich people because she realizes that as her strength fails her, she will not be able to care for the child. Better that wild horses trample her beloved grandchild in the street than he be taken to the institution. And better that she wander the streets in her old age, working where she can so that she can save the pittance she carries with her for her burial. Better that she should trust the ordinary citizen who finds her to read her note and do her will than to beg charity or have her money and her body stolen for the support of the workhouse. It is with sadness that we can look to our present alternatives after more than a century and realize that they are essentially the same—the caprice of charity in the community or the ransoming of body and property for "care" in a large institution.

One hears federal testimony of children being shipped across state lines to huge warehouses. One reads government regulations suggesting that private charity should build group homes, to answer the need, rather than stimulate generic agencies where people can be integrated. One see millions upon millions in Medicaid money used to incarcerate people in large institutions controlled by bureaucrats and the medical industry rather than to pay for meal services, sitters, home aides, and the like in their neighborhoods. What powerful selfish interests are at hand to keep people in their places. Civil service unions, the construction industry, financiers who make huge interest on bonding, and the medical industry, which control standards, staffing, and service-supply contracts, all stand to lose a great deal if the public accepts people with handicaps in its midst as citizens with the right to self-determination and dignity.

What would be entailed in honoring such a right? Some people define a right as a limitation on someone else's power. Ira Glasser, executive director of the American Civil Liberties Union, points out that the Bill of Rights is worded negatively to reflect this construct. However, it is easy to see that for a person with special needs, it is not sufficient to simply limit the state's power to physically incarcerate him. We may have to limit other people's "right" to make money out of him as well.

Private charity had never been sufficient to counter neglect, even if it had so desired. Therefore people like Dorothea Dix traveled around the countryside begging and cajoling people to build institutions for the care of needy people. Today some parents are asking that institutions be destroyed; others are beating down the doors to get their children in. This is not so contradictory as it sounds: some parents perceive that community supports, respite in family homes, baby-sitting, attendant service, and so forth, will never be developed on a large scale while institutions eat up all the money. Other families, because they do not have those supports, come to the point of disintegration, needing fulltime, final relief at any price. It is obvious that we have to put forward positive supports in the community so that people will not be bounced endlessly from the inadequacy and stigma of private charity to the inadequacy and stigma of bureaucratic response. "Liberty" loses its glow when it means that one is free to die in the street like Betty Higdins, to suffer alone without respite, or to accept services at a painful psychological price, as many families must presently do.

A choice similar to this was presented to us when Jeff was just over a year old. We had made arrangements to have him evaluated at a Shriners clinic in a city about seventy miles away from home. The doctor had suggested that perhaps I had better sit down before hearing what he had to say. It was the first time we were told that Jeff's legs were paralyzed. Though he moved them very little, this realization had not come fully upon us. Jeff could, however, become ambulatory with braces, the doctor continued . The price for this orthopedic care and therapy was that we would have to take Jeff to live at a hospital in a different state, several hours away. Visiting was strictly limited, and we would be required to sign a blanket permission slip giving them the right to do any and all surgical procedures they felt necessary. We anguished over this for a full year, reading and rereading the letters and forms. Finally we decided that the price was too high. This separation and signing over of our child was not possible for us as the price of charity.

Sometimes "charity" and begging exist in unlikely places where one is scarcely aware of what is happening, even in public hospitals. After we received Jeff's brace, which at that time consisted of a jacket for his upper torso attached to the pelvic band and full leg braces, I could not bend him in it. I checked and rechecked to be sure the hips were unlocked and that nothing mechanical thwarted his sitting. Carl pointed out the discrepancies between the pivot points of the brace and where Jeff bent. A thousand-dollar pair of braces which could not be used would interest people because of the labor invested, I thought, even if Jeff himself did not interest them.

But I was wrong. The bracemaker refused to see us without an appointment and a referral from the doctor. The doctor's office at the rehabilitation hospital shunted me back to Mrs. Braintree, who was in charge of the clinic. She informed me that I could not see the doctor because there were lots of people who needed the doctor more than we did. She proceeded to tell me about a nineteen-year-old amputee and boys who got hurt fighting for their country. I ventured that we meant to wait our turn, but she said the doctor was always busy, that there were other people in the world besides us. After all we had been through, she would still take it upon herself to bar us from help! She clearly meant that we were not to come again. Finally I called the therapist who had once given up his lunch hour to stand Jeff in the *Life* magazines. In near tears, I explained the situation.

"Mrs. Braintree is an ass," he said abruptly. "She's caused lots of people all kinds of trouble." He suggested that I bring Jeff in, that he would look at him. In that way he could call the doctor, having established that something was wrong. Because of his charitable response, we were able to get help. Some unlikely settings, even those receiving public monies, often operate upon the basis of someone's "charity" and values. If you pay your money, and beg as well, you may still be denied, for some institutions are accountable to no one.*

If public hospitals are unlikely places to be operating on the basis of personal bias and individual charitable impulses, the church might be the single place one would expect to find charity in its most noble form. We did not find this to be so, and since we were both ardent believers as well as active, supporting members, this caused us painful disillusionment. When Jeff was about three we prevailed upon the minister to visit us for the first time. We were worried about everything from our ability to cope from day to day to what would happen if we were accidently killed. We wondered, on an immediate basis, if there were people in the congregation who would allow their children to baby-sit with Jeff or read to and play with him.

It was a heartbreaking session for us. Pastor assured us that we should not feel guilty to place Jeff in an institution. Lutherans were among the first to recognize the special needs of the retarded and, in fact, ran the largest institution in the world for those kinds of people of all ages. No, it would not be possible, he said, wagging his head solemnly, to ask the teenagers to "become involved in something of this nature." He made our plea for help sound like some dirty kind of business. Perhaps, if we insisted on keeping Jeff home, we could sponsor a girl from Germany who would work for me for a specified time in return for air fare, room, and board. We were appalled at nearly everything he said, and yet we took it seriously because of the authority he represented. This led to further internal conflict for us.

I tried to forget my pain that somehow Jeff's name was never recorded on the cradle roll, although it stared me in the face every Sunday when I took him into nursery, and the many Sundays I stayed to tend the children. I mentioned it to several appropriate people, but it was never added. When I asked if Jeff could go into the regular three-year-old class if I remained with him, I was turned down flatly. Then I tried for years to set up another class. I sent for materials, set up and attended meetings, and viewed films, but nothing materialized. In the beginning they said we could not set up a class for just one child, and I made massive efforts through other churches to locate more children. In the end the class fell through because there was "no room," not even for one child.

Meanwhile, Pastor sent a long line of assistants and even a minister of education to visit with me. Each time I tried to explain our needs: a class where Jeff was accepted and could learn so that Carl and I could attend church together. Mr. Relyea, the minister of education, misunderstood me and my commitment to the church and the concept of Christian education to the extent that he said, "It appears to me what you are looking for, Mrs. Pieper, is a free baby-sitter."

This remark came nearly on the heels of his comment that they could not get "just anyone" to teach the class, after I had indicated that I would like to share joint responsibility with the special education teacher they had in mind. My own frustration and anger came to such a pitch that I felt easily capable of picking him up bodily and heaving him down our road. Instead I felt myself dissolving into tears and hurriedly asked him to leave. There was no point in talking further.

At this very point, Marge Babcock, Jeff's special friend, rang the bell. I retrieved Jeff so that they could visit in the kitchen before getting Mr.

Relyea's coat. After a few minutes, in which Mr. Relyea saw and heard Marge and Jeff talking together, he said, "Are you sure he's retarded? I think it might be an emotional problem with him." Either way, there was no room for him within the church.

After Jeff's first year of school, we decided to have him attend the cerebral palsy summer day camp in the heart of Albany. This meant that we had to get up early and, in addition to going through Jeff's whole routine, I had to pack separate lunches for Jeff and for Julie and myself. We had to travel country, town, thruway, and city traffic. This was not helped by the fact that Jeff still had temper tantrums of the first order when I shifted the car out of first and into second gear. The first few days he screamed and cried all the way. One of the sisters had asked gently, "Why do you bring him, Mrs. Pieper, when it upsets him so?"

"I don't know. Except if I gave in to every one of his tantrums and withdrawals, he'd still be home in a crib. He'd never have learned to enjoy a record, a story, or a song. Even the things he loves, he used to fight. So I just keep trying," I admitted honestly.

In truth it was a horror for Julie and me. We had nothing to do. Every morning we went to a nearby park, but it was a joyless place. Police cars rode by, endlessly investigating broken glass or bent paper clips which had been thrown into the wading pool. There were no swings in the morning, only the naked steel swing frame. Everyday at precisely one o'clock a brigade of attendants, reminiscent of the broken inmates of a mental institution, engaged in a surrealistic pantomine in which they attached real swings which would remain in place for a couple of hours before being taken down again. The rest of the equipment was locked safely behind heavy, twisted wire fences with extensions of barbed wire above, such as one sees around prisons.

When the area opened, there were too many rules for either Julie or me to remember. No one could enter the play area with wet pant legs from wading in the pool. This meant that I had to bring extra clothes for Julie. No one could enter barefooted; no one could run. No one was allowed to shout or raise his voice. The equipment could only be approached from one side. A whistle sounded, and the children embarked en mass; another signal sounded, and all of the swings slowed and stopped in near unison to disgorge their cheerless occupants. The riders left through roped aisles, turning smartly at right angles to follow arrows marking the way. It surprised me that any one bothered to use the area at all.

Once we tried to sit on the grass but were reminded that it was against the rules. On rainy days we had to sit in the car and play games. Once or twice we went to a thrift shop or rode through the downtown to find parking space near a museum. There was none. So, day after day, we stared past the luxuriant lawns to the new construction of the South Mall as it rose imperceptibly to dwarf the lovely cathedrals and older buildings with almost obscene authority. When done, the new city, rising out of the old, but bearing no resemblance or relationship to its roots, would house nearly 20,000 bureaucrats. There would probably still be no room for us, and our needs might reach this modern bastille just as the sounds of construction met our ears, distorted by the distance and dulled by the constancy.

One morning we presented ourselves in high spirits to the swimming pool director at the park to ask what time the cerebral palsy camp would be coming over. I had heard that Jeff might have swimming lessons there, and though I knew it would be tough on Julie to simply watch, we were both excited. The director eyed me suspiciously.

"Why?" he wanted to know.

I was fully taken aback by his manner, and explained that we wanted to see Jeff go into the water. He did not know; sometime before the pool was open to the general public. He challenged me to another "Why, what difference does it make to you?" I told him that I was trying to plan whether I should go home or wait. "Why?"

"Well, I have work I could be doing at home," I replied with a nervous laugh.

"Well, ain't that tough. I've got work I could be doing home too, lady, instead of teachin' your crippled kids to swim while you parents are out having yourselves a good time," he emitted with the real malice.

I felt as if he had slapped me and almost fell away from him. I was embarrassed for Julie to hear this and wanted to flee backward in time so that this could not happen. I wondered at his hatred, and at my naivity for falling in with his baiting. Tears stung behind my eyes and I felt an urge to attack him. As I

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*Section 504 of the Rehabilitation Act of 1973 may allow people to challenge agencies which use federal monies and discriminate.

stood stunned, fiercely clutching Julie's hand, an old man with a mop and a bucket startled me at my elbow.

"Don' mind him, Miss. He's mean ta everbody. Just don' pay him no mind, tha's all."

It may have been just such attitudes which contributed to a mode of thinking prevalent in voluntary association leadership—that you cannot ask anyone else for your need until you have given sacrificially yourself. Indeed, this principle is put forward in books on fund raising and is taught formally in classes in universities. We were to meet it under more emotionally charged circumstances. All of the parents at the Center were invited to a dinner and urged to have their friends attend too, so that we could hear about the planning being done to insure our children's education. This pattern was to become familiar, for though there was a board of directors, its membership was pretty much in-house, and those represented were those who could "do something" for the association. That is, they could either bring in large donations, muster volunteer help, or insure favorable consideration on everything from zoning to approval of grants and programs through governmental agencies. Parent or consumer input in planning was obviously not chic, and could prove to be a definite liability to the benevolent traditions these men represented.

I was utterly dumbfounded that the procedure approximated that used in church. First we were made to feel that while we did not do all of this planning and spend all of this time, we were fortunate to have these more valued people interceding for us. Furthermore, their dedication was to be a model for our own lives and for our own giving. They had, between them, raised several thousand dollars. If these people cared for our children, could we care less? And if we would not do for our own, could we expect anyone else to forgive them their needs and give? The prepared pledge cards were passed out, signed, and deposited at the alter of sacrifice, the head table.

If I remember correctly we made our pledge for $250, which was to be spread out in payment over two years to be painless. Since it was the lowest amount expected, it could not be considered sacrificial—unless you were buying secondhand clothes for yourself and family and unless you came to believe, as I did, that you were selling out on your child's dignity and rights in creating segregated settings. Then, the contribution, whether token or sacrifice, is filled with anguish.

Another major fund-raising event was the telethon. We hastened there without lunch, after church, through a snowstorm, to arrive at the prescribed time. After a struggle parking and maneuvering Jeff's wheelchair through the snow, we entered a large armory. Jeff was frightened by the dimension of the thing, even before he saw the lights and heard the noise of the central arena.

Our children had been billed, in letters to parents, as the real "stars," although celebrities from television would perform. I wondered what our children would be required to do for star status. Well, just be themselves, I was assured. Just sit there. At some deep level of my mind I was disquieted by this.

When we rolled into the curtained area of bleachers reserved for parents, a child's voice rang out. "There he is, Mom." I was conscious of being out of touch. We had only recently bought a portable television and still did not watch much. I did not recognize famous personalities. At least someone else could get a thrill out of the venture; I was just there to do our duty, to present Jeff as required in exchange for his place in school.

"There he is. My friend, Jeff Pieper," the voice enthused again over the din.

I was touched. Here, where I supposed only celebrities would rate such attention, a boy was excited to see Jeff. The boy was bright and moved without too much difficulty. He probably would have been acceptable to a public school except for his "bizarre behavior." Everyone had remarked about how he had taken to Jeff, really thought Jeff was "cool"—which he was.

Jeff sat for a couple of hours under the hot lights. I noticed how the able-bodied children filed by the fishbowl, where they dumped the coins they had begged from their neighbors. I saw how they strained to get a good look at our children, who were separated from the public by purple curtains draped beneath the cordoned aisles. The beggars and the benefactors.

They had come to pay their respects and to assuage their curiosity. How unfair this was to both groups. Both were being used by adults and systems. Both were taught, by modeling the behavior through public schools, that some children must be interred away from other children; that some must be dependent, in carefully prescribed ways, on others who have more power and who therefore have a responsibility to be benevolent, always on their own terms.

The lights, the tired smiles of stars of yesteryear, the pity, the pleas to give, the close-ups of Jeff's paralyzed legs, the raucous crescendos of the band announcing new totals issued forth in a vacuous and screaming counterpoint to everything I knew and loved about my son. And everything I had hoped and believed about my country. I hoped that I would never have to come again. I hurt in the depth of my soul, and I felt embarrassed, shamed, and angered at what I was asked to do to my son.

I would not tell Jeff he was a "star" for being crippled, that people wanted to look at him across barricades and through television screens but would not accept him in their communities. I could not believe that this was the only way people would come forward to help. For they had demonstrated differently. Above all, I would not believe that children were the ones keeping other children out of "their" schools. Administrators on both sides—those who did not want our children in their schools or on their budgets and those who earned a living providing for "the less fortunate"—were the ones who made the decisions. Children imitate the attitudes and values of the adults who are in authority, and these grown-ups, instead of throwing their value and status behind the underdog, set an example of exclusion and discrimination. Thus charity was necessary, both to ameliorate the situation and to underwrite its continuation.

The basic attitudes which say that some children are not entitled to services can make even public monies into charity. This is most certainly the case in the family court procedures which exist in our state and others. When the cost of private tuition for a school-aged child goes beyond the allotment, the service provider holds the family responsible for the remainder. He may suggest that the head of the family file a petition which "prays the court" for mercy and funds and signs before a notary that he is unable to pay the additional costs. Although several legal precedents have been set which clearly hold the state constitutionally liable for all tuition costs, it has been necessary for parents to fill out means tests listing all income and liability, to hire lawyers on a case-by-case basis, and to appear before a judge.

Why do courts take part in the demeaning of innocent people? Does this not amount to victimizing the citizenry? If this were an unconscious blunder, one might feel differently, but every judge who is qualified to sit in decision knows the legal precedents and the constitutional requirement. Why then this shameless show of authority?

Some liken our telethons to the circuses in Roman times where people victimized each other. We might wonder how long this would have lasted without official approval of the Emperor and of the state? Further, we might even inquire if the people were not seduced into that forum by a corrupt state? If telethons are the people's circus, family court is the state's sanction. Image-wise, it suggests that having a handicapped child is a crime. It matters little to the overall issue if, having endulged the brutal procedure, the Emperor turns thumbs up now and again.

Even progressive legislation such as the Education of All Handicapped Children Act (P.L. 94-142) on a federal level underwrites the theory that all children are *not* entitled to free, common education on the same basis as the Supreme Court held in *Brown v. Topeka Board of Education*. It rather recognizes that some children are so undesirable that the federal government must buy their way in at the local level. The federal government will preserve the local level's discretionary power by making the legislation permissive instead of mandatory for states. Further, if the state decides to give up some of its discretionary power to exclude, it may receive money incentives. But what is the cost? What is the trade-off? Children must be labeled and stigmatized in order to participate in "free" education. This is always the price of charity.

Some would have us believe that we can resolve our differences so that everyone wins. With the late Martin Luther King I believe that ultimately that is true. In the short term, someone always loses. Perhaps one individual or group loses a little status or control over someone else's life. That is not fatal. It may even help people to feel better about themselves in the long run. For example, people who have resisted having a group home in their neighborhood to the extent of court action have later become good neighbors to the residents and have admitted that they have grown in their feelings for other human beings.

To come to the best solutions with the least amount of adversary process we need to be ruthlessly honest in clarifying whose interests are being served at every turn and what the influencing factors are. Some corporations have ESP (economic, social, political) teams which attempt to demystify the forces acting upon their business. One company measures wind direction and rainfall in Asia to predict crop production and provide input to the price of grain and therefore the cost of money. Some top-flight managers have reversed the Persian messenger syndrome, where the bearer of bad news is beheaded, by rewarding the valid prediction of trouble. They say they do not mind bad news if they hear it soon enough. They depend upon their resources and contingency plans to forestall disaster or turn it to advantage. In contrast, the human-service industry seems content to forgive every consequence after the fact because it represented someone's good intention. When things run amuck it is still standard to blame the victim or his family. There is little effort to make scientific inquiry or to countenance even the most obvious factors.

In the nineteenth century the beginning of the industrial revolution required large numbers of workers in production. Workhouses were intentionally horrible to keep people in the labor market and to reduce costs to employers. Today we have a different situation. We have a surplus of labor. It is estimated that by the 1980s we will need only one-third of the present work force in production. In our time we have seen the advertising industry bloom and grow, taking up the slack in workers and simultaneously helping to increase consumption and therefore the need to produce. We are now seeing in increase in the human-service field which may create employment and simultaneously dependeny, thus complementing social and economic needs. We may expect to see all manner of mechanisms to shrink the labor force, and some of them may be pernicious.

We have already seen a ban on child labor and the exultation of play as a child's province, increased higher education, shorter work weeks, early retirements, a massive persuasion industry to increase consumption, and a vast leisure industry to lure adults out of the job market. In this context people with disabilities will have a harder time "proving themselves"; that is, demonstrating that the costs of habilitating them are paying off. We see a trend toward human-service management which may tend to keep people dependent upon whatever kind of institutions the powerful decide to offer. Euthanasia and neglect may increase, thus building in elasticity so that dependent populations can die or flow in and out of institutions in keeping with what costs are acceptable to taxpayers. This will not necessarily be a conscious scheme. It's danger lies more in citizens being unconscious of what is happening in time to act. "If you can't forecast, all you can do is react," says one of industry's superplanners. We must learn to analyze influencing factors and plan accordingly.

In this context we must do everything in our power to see that individual rights are acknowledged and that services are provided without discrimination. This will entail an ideology that insists upon the worth of every individual and the provision for need as a right rather than subject to caprice or charity. It will also mean we must engage in long-term planning and empowered coordination so that services can be provided in cost-efficient ways. If someone is going to "lose," let it be the business or voluntary agency which loses a little of its discretionary power over when, where, and how to provide, rather than the individual who must be neglected or custodialized in order to indulge that choice. In our need to give, to be charitable, let us lose our discretionary power to donate only through prescribed and traditional channels, which may enhance established authorities more than devalued individuals. Perhaps we can give to help others establish their rights to dignity and self-determination. This will require new ways of organizing and advocating, as well as dialogue and close friendships between professionals and consumers.

Chapter Ten

Organizations

Before Jeff turned three, I received a call from a mother looking for children for a nursery school. I explained Jeff's condition, adding that I felt badly that we live in the country. Jeff could benefit from being near other children, even if only to watch their interactions. Her pity and ill-contained horror drew lines around that possibility.

I called the Association for Retarded Children, only to be informed that they had no classes for preschool children. Furthermore, they did not take any physically handicapped children in the school-age program. I asked why on both counts, and was told that "these children" do not benefit from education until they are older. Additionally, the building was inaccessible to anyone who had trouble walking. I could hardly believe it. Even more disturbing was the manner in which these shortcomings were put forth.

When I asked on what basis they concluded that very young children did not need special attention, she replied that all of their consultant authorities agreed on that issue. I pressed her for names, and finally she said Dr. Callahan. She began to describe his illustrious affiliation with Dr. Cooper and Dr. Hayes. I told her that many educators felt differently. She was unmoved, obviously more impressed with what a medical doctor said about child development than in what educators said, although I was sure nothing in Dr. Callahan's training could warrant such a preference.

I went to the local cerebral palsy meeting. The parents pointed out that our child was obviously quite different from theirs. I tried to have them understand that Jeff needed therapy and the opportunity to be with other children. Mrs. Braintree called me aside and gently explained that Jeff was retarded and that they did not accept retarded children in their program. I was nearly in tears of frustration, for it seemed that no one would help. In addition, as she looked at me with those cold blue eyes and fixed smile, I knew she thought I was crazy for asking.

Every time I had the experience of being an outcast amongst the outcasts, I felt so utterly deflated and limp inside that it was all I could do to force myself to pick up the telephone and make another call, write another letter, or attend another meeting. Hundreds of parents with children who do not fit into any easy category have since expressed these same feelings of helplessness and frustration. The rejection and humiliation cut so deeply into an already wounded spirit that it is self-destructive to keep subjecting oneself to this.

One of the groups from which I held the highest hopes of gaining some emotional support disappointed me most. I had heard that a new group was forming for parents of brain-injured children for precisely the reason that their children and their families were little understood and lacked services. Two of the people I had gone to college with were instrumental in forming the group because they had a brain-injured son. I felt the trip to Albany would be worthwhile, since these people would share a common philosophy about child development.

When I talked to Marcy, explaining Jeff's problem, I expected real interest and concern, even though I knew her son was not as bad off as Jeff. She looked at me with the same cool, condescending pity as others who were personally removed from the problem.

"Oh, we don't have any children like that! All of our children are of normal intelligence or above. They are not retarded or disturbed or anything like that. Our children have learning disabilities."

My frustration was enormous. No one seemed to see neurological damage as a matter of degree. If a child had this much or these certain symptoms, he was "in." In some cases it seemed as if parents were bent on making their kids into perverted status symbols by creating fashionable conditions. Therefore if a child exhibited a little more damage than the prescribed amount, or was contaminated with other symptoms not recognized by the "experts," he was "out."

We became conscious of a good deal of comparison between disabilities. The children got lost in the fray. "Brain injured" did not want their children associated with "retarded," parents of children with mobility limitations did not want their children associated with either "brain injured" or "retarded," and parents of the "retarded" drew constant bitter comparisons about how "mentally ill" and "crippled" kids got all the money. Nobody wanted anything to do with a child like Jeff.

It is not easy for a parent who loves a child and holds that child precious to have him devalued at every turn. Some parents turn their energy and suppressed rage inward, literally destroying themselves or their families. Others find solace in this tight little family circle and withdraw from the world in quiet martyrdom. Some retreat into personal change by becoming submissive to all authority, both spiritual and earthly, feeling that rewards in a future life will be directly proportionate to their forbearance here. They may even encourage others to submit to all earthly authority, no matter how evil, believing that then somehow conditions will change for the better.

Others ostentatiously reject personal change and set out to change the world for their children, or so they believe. They usually rely on educating the public and creating their own separate "special" services. Without meaning to, they may actually demonstrate that they *accept* the public assessment of their children as less than other children. By their actions, if not their words, they tell the public that it need *not* change: exclusion of children may continue; blaming of parents may continue; personal liability may continue.

Personal liability and acceptance of a one-down position will increase, in fact, for parents will provide their own services. Instead of demanding excellence in education and health care for all children in settings as local and ordinary as possible, they underwrite their special needs with special services available only to some. Thus, what passes as changing the world is just a variation on personal change and helps to reinforce old attitudes and discrimination.

Some weeks I attended meetings three nights in a row, and often Carl accompanied me, especially when someone from the education department was trying to explain the education law and its policies or the new federal aid available to certain organizations for certain services to the handicapped. Of course, we had already learned that each organization tended to champion one type of disability and to jealously guard and expand services for the select few being serviced instead of reaching out to others. We also saw parents locked into a life-and-death struggle to raise funds to support those services. It was sad, but understandable, that they did not want anything adding to that burden.

They were so busy raising money that no one seemed to have any real awareness of what additional public funds had become available. The theme song was, "If *we* don't do it, who will? These are our children and our responsibility." They were so busy hugging their grief and rejection to themselves that they did not even know when the public was willing to help out, and certainly could not educate the public to provide integrated service. Simply by sharing information we had heard at another meeting, Carl and I were able to tell them about new funds available to replace some of the hard-sought charity they were begging.

There was no communication between groups and indeed, rather than being thanked, we were viewed suspiciously when we mentioned what we had learned elsewhere. From our perspective of not quite fitting in anywhere, we could easily see that all of the self-flagellation and frenetic activity, all of the infighting and backbiting, weakened the potential for ever obtaining the full range of lifetime services our children would need. Even worse, it turned parent against parent and parent against child, because the commitment was to providing services instead of providing emotional support and friendship for people.

Once when we attended a local cerebral palsy meeting, two young people with disabilities spoke of their dilemma. The young man's speech was agonizingly slow and barely intelligible to us, for we had never heard anyone with the condition speaking for himself. As young adults they had no programs at the center and, he said, received no support for their concerns. His companion said, "You liked us all right when we were young and cute, but we had to grow up. We couldn't help it. It's like that old saying, 'The only trouble with a kitten is it becomes a cat.'" Her voice was bitter and choked with tears.

Carl and I were tremendously moved. We could see both sides. This was the inevitable result of trying to take all of the "blame" and responsibility upon one's self. The parents were caught up in providing for the limited few. They were already spread too thin. Many of them had never heard the term "architectural barriers," they had no legislative committee, and they seemed to look no farther ahead than the next summer camp or the swimming pool they hoped to build. Perhaps they did not think their children would grow up, or perhaps the children would, by then, be "cured." If and when they matured, it would be time enough to worry about employers' attitudes, transportation, and housing.

But we knew the tragedy of social isolation only too well from our own experiences and from what happened to my grandparents. Even the newspapers pointed up the dilemma for those who were sensitized to see. In Albany I testified that families of the disabled cannot afford to make their homes accessible to independent wheelchair living and that a person can be "rehabilitated" all of her life and still not be able to find a job or use public transit to get there. On the street outside, a paper appeared with a small article, "Cripple Dies in Fire." The story noted that the man had apparently dragged himself out of his wheelchair and across the floor, but then could not get the door open. There was, of course, no public outcry. He was only "a cripple." The man in the street did not realize that there was no low-income housing available which did not require the ability to climb stairs or which would not be likely to trap someone above street level. Perhaps those who had never thought about it did not realize that people would rather live among others in the real world instead of in a nursing home, even if it meant risking their lives.

I could see my son in every "cripple" disregarded by society and myself in every parent who was ignored or mistreated when asking for help. Area newspapers and television stations carried a story about a sixteen-year-old in California. The stories ran for several days on end and told of officials, authorities, and experts *discovering* the girl when her mother applied for welfare aid because of the family's financial condition. A great deal was made of the fact that the girl was mute. This was attributed to the "home situation" and lack of communications. It was duly noted that the family had neither a radio nor a television. In short, the parents were villified for keeping the girl hidden and causing her condition.

I made photocopies of the articles and sent a letter to Governor Reagan of California, asking that he institute an independent investigation. I sent copies to President Nixon and Governor Rockefeller. The plight of the child was only "discovered," I noted, when the mother of her own volition went to authorities for help. There was no screening program or outreach of governmental or public concern before that time. Many parents, having greater resources, turn themselves inside out looking for help. In particular, the parents of autistic children could testify that muteness may remain after extensive travel or bankruptcy from seeking help from all manner of experts. How could parents be blamed for the lack of concern by fellow citizens and the failures of experts?

What were the backgrounds of the people at the hospital issuing those damaging statements? I could only imagine the psychological torment the family was suffering at the hands of suddenly concerned authorities who apparently called in the press. I wondered if these experts were, in fact, doctors who passed themselves off as authorities on the nature of human development and all manner of other things in which they were not specifically trained or qualified.

How in the world did Pericles or Lincoln learn to speak if one needed a radio or television? I did not know any details about these people, but I *did* know the general plight of a family with a retarded child in this society. I *did* know what was coming through the mass media the full breadth of our country. How could a family survive such treatment?

Predictably, the brutal publicity culminated in the father's self-destruction. I was grieved inside my soul. I had resisted the urge to send copies of my letters to the Sacramento papers, to the out-of-power party, and to legal-aid groups which might have provided some check upon the situation instead of succumbing to a cover-up. But I did not want to do anything which could be construed as muckraking or rabble-rousing. I had once again gone through the established channels, the ones I had learned to trust for justice in seventh-grade social studies; the ones which let me down again and again as a mature citizen.

Now a man was dead, technically of his own hand. A mother was grieved, and the child would, no doubt, be treated to the prescribed help which might place her in a foster home or institution. I doubt that any formal charges or proof that the parents were unfit were promulgated. I doubt that the spirit of due process was upheld. I doubt that any support services such as parent training, homemaker service, or special education were offered to help the family.

In my subsequent experience, as parents appealed to me when their children were taken by authorities—one time while the father was at work—a problem-solving approach by the authorities has almost never been taken. The solution seemed to consist wholly of blaming the parents and taking the child away. Before my own knowledge of the difficulty in obtaining service, I would have internalized the position of authority against the individual. The officials know best. In fact, if I were ever to grow up to be an ordinary, white, middle-class American I should not ally myself with the elements of eugenic theory and the problems of retardation and poverty. Besides, everyone said, there was nothing one could do to change things.

Most of all, I wondered, where was the confidentiality and professionalism in a case like that of the mute girl? Over and over I had seen the worst aspects of confidentiality and professionalism—namely, secrecy and elitism—hurt people who were already vulnerable. But how did it happen that people within the helping professions had contributed to a coast-to-coast assault? Were there no charges against them? Were they accountable to no one?

Recently our community advisory committee asked that parents be allowed to attend the comprehensive assessment where they and their child are discussed by a battery of experts. The physician in charge refused, saying that it would not be good for parents to hear experts disagreeing among themselves, and that the information which might come out could traumatize and psychologically damage them. Several people attested that what they had *not* known had damaged them and their child more than anything they were told. They affirmed that they had a right to know.

The doctor remained adamant. I asked for referral to the body of research and evidence that parents would be traumatized by hearing expert opinion firsthand. "Well, it's obvious. Don't you see! What if that poor mother had heard Dr. Callahan? What if she'd heard him say, 'Well, of course the child's retarded. The *mother* is retarded'? She could have gone off the bridge that very afternoon. Then I'd be legally responsible!"

"Is she retarded?" I asked.

Aghast that I would insult the woman, the doctor replied, "Of course not! She's no more retarded than you or I . She is just depressed. No one has ever told her anything. She doesn't know what is happening with the child. She is not retarded. That's stupid. She's fat and slovenly and depressed, poor thing, but she is not retarded!"

In my opinion this doctor is not protecting a parent. She is protecting a colleague's privilege to make irresponsible statements. In fact, she is protecting a privilege which extends to a whole class and which creates a burden upon its members as well as its victims. Furthermore, she is protecting the image of professionals as godlike and infallible by not allowing people to see their honest disagreement. This renders a parent alone and helpless, sometimes causing him to give up an accurate perception which could contribute to the child's treatment. The professional has the burden of being infallible without testing his ideas against the person who knows the child best. Everyone loses.

There is an authority which does not rely upon secrecy, mysticism, and elitism. It derives from competence and relies upon input from ordinary people as well as esoteric sources. The authority of competence is recognized universally. Authority which does not rest in understanding and service to people must rely constantly upon what sociologists call dominance gestures. Over the years I was to experience the full array of these maneuvers as I tried to find the safeguards, the checks and balances which could protect ordinary people. Administrators and professionals take refuge behind their desks, in their titles, in their uniforms, and in other means of distancing themselves from the people they seek to serve.

Legitimate concerns and intuitive knowledge are discounted in every possible way. I was told that there was no problem; that obviously I was an exception; no one else was complaining. Or, I was told that they, the experts, were well aware of the problem. It was being taken care of. Sometimes I was told that *I* was the problem; I must adjust. Sometimes I was invited to prove the existence of the problem through a task force, commission, or other bureaucratic response, which usually wound up being the end in and of itself, instead of a means to an end. A few times I was offered jobs which I felt would only co-opt my energy for change. Once, in an effort to discount and discredit my observations, the commissioner of health wrote to the minority leader that I was not as "stable" as other people. But most of all I was told that no matter what I did, nothing would change. It was all downhill, or uphill, from here—depending upon the person's view of human nature.

But something else began to happen, too. Bureaucrats began to seek a moment with me after emerging from a head-wagging session which one friend calls the "gentleman's agreement." The conspiracy of silence would be broken with tentative admission that there might be a problem, and that I might be able to do something about it if I found other people to help. I began to be interviewed by reporters after giving testimony, and some even came to our house to look through my files and to borrow material. Articles of real insight began to appear in our local papers. Interesting pieces of information began to appear in the mail describing some encouraging breakthrough or new approach to an old problem, or just a note to look into something. One day a man in his eighties called to offer money for a right-to-education legal suit for handicapped children. I did not take it, for I perceived properly that I would not be able to find an attorney; but when I told my friend she burst into tears. We were both tremendously moved to have someone reach across the generations to our children in the name of helping and justice.

A couple of high-level administrators called, sometimes from pay phones in the lobbies of their buildings, to offer argument, opinion, encouragement, or strategy. A conservative senator's secretary called and talked until three in the morning. "Your only problem is that you are innovating for change on the wrong level," she said finally. "You have got to think bigger."

Most of all we shared a feeling that we were being victimized by something bigger than any of us individually; not by people, but by the systems in which people work. It was something impersonal, like a physical principle: the physical force of a great wall of water, the dynamic inertia that drives it on unless it is stopped by a more powerful external action. It was an irony that the structure which now loosed havoc upon us was built by and for the people. Still, many of us began to be hopeful, to respect each other's positions, and to think we might be able to change things by working together.

Chapter Eleven

A New Birth

Even as I sat, writing, Carl's brother Bob called with news of their fourth baby. As I listened to one side of the conversation, I became more and more puzzled.

"Oh, really? Oh, I'm sorry. That's sad. I'm really sorry. How do they know? That's too bad. Well, at least Eleanor is all right."

At first I presumed that the baby had been born and died. Then I surmised that the baby had not been delivered yet but was nonetheless dead.

"What happened?" I asked, bewildered, when Carl had replaced the receiver. "Is the baby born?"

"Yes," Carl answered quietly. "But it's a Mongoloid."

My initial reaction was of shock at his use of "it." My day-to-day work has made me sensitive to the use of labeling and rejection. I forgot that all new babies are "it" until one pronounces which sex the child is. He knew that the baby was a girl, but not her birth weight, when she was born, or her name.

Some of my good friends have children with Down's syndrome. The children do well, and their families seem beautiful to me, although I know times are difficult and they experience pain and rejection. But basically, it seems like no big thing to be born with that difference. My impulse was to call back immediately and to express some sense of joy at our niece's birth.

In all that we had been through, my greatest sense of pain, aside for my hurt for Jeff, was that no one would allow me to rejoice or to hope. I could not let Bob and Eleanor suffer the same suppression. It was two days before I could reach my brother-in-law. When I did, I realized that for him the event was an unmitigated disaster. He was bent on grief. He could scarcely comprehend questions about the baby's weight, when she was born, or her name. He expressed appreciation for my call, but perhaps my "hope" was as oppressive to him as people's silence and withdrawal had been to me.

Being on the other side of the situation, I felt the inadequacy of reaching out without intruding and of giving support without telling them how I feel. It may be this sense of inadequacy which has led us as a nation to hand over many of our important life milestones to doctors, hospitals, social workers, textbooks, and greeting cards. We have forgotten our rituals, sanitized our pain, and given over much of our grief and celebration to commercial arrangement.

I have often hoped that I could know the day and hour of Jeff's death so that I might have him die in my arms rather than in some hospital with nurses running in and out, intruding upon the communion of dying and of losing a precious part of myself. I have sometimes felt that I would want to dig the dirt, hammer the coffin, and pick the flowers, exhausting myself with the labor. For me this would be the way to acceptance and release, to literally commit a loved one to the earth and to eternity with labor and personal ritual—just as it seems fit to me that babies should be born within their homes with appropriate help and companionship when a woman wants that. Other people have different needs and different feelings.

I could only experience the possible feelings of my sister- and brother-in-law through my own experience and the experiences of friends, and to wonder about those feelings through the expectations of experts. Would they, for example, feel the sense of loss which is so often mentioned? Perhaps they would, for they had known the birth of other children. I was not grieved at the loss of a "normal" child when Jeff was born. How could I grieve an abstraction? How could I grieve a living child? Certainly nothing in the formal education I had received could have prepared me for Jeff. He was a surprise of the first order; perhaps a disappointment. I did not feel that at the time. Mostly I hurt because he hurt, and because I could not hold him. In my innocence I presumed he was wonderful. Even his wrongness heightened my sense of wonder at his complexity and of what was perfect.

It is only as I know Jeff and his specific personality that I can look at boys his age, whether lifting their voices in a mighty disciplined chorus or bloodying each other on a football field, and feel my sense of loss. It is only as the curvature of his back twists him ever more cruelly into shapes I do not know and limits his movements more and more that I grieve. That grief was not a postpartum stage, but rather a growing hurt. I hope for Eleanor and Bob that it is a postpartum stage.

Surely the violation of expectancy in the birth of a child can cause a deep sense of disappointment or loss. Just as surely these feelings are not indicative of how *all* parents feel or how an individual parent will feel five days or twenty years later. My friend Betty was one of those who felt keen disappointment at the birth of her baby with Down's syndrome many years ago. She tells of her husband's response to her pondering that perhaps they would all be better off if Lisa would die.

"You don't mean that," he had put forth with injured pride.

"I do," Betty had replied resolutely.

It figures that they had that kind of open, trusting relationship. Today Betty is one of the leaders in the movement for disabled people. She questions here, prods there, and is as ready to change, even after investing her energy and time, as she is to ask others to change. Above all she is honest in her feelings and inquiries.

As Betty and I talked into the predawn light one evening, it was obvious that she had brought Lisa up with the same honest approach to life. At one point Lisa called out, "Quiet!" Not angry, not apologetic. It was a simple assertation of her right to be undisturbed at three in the morning. At the same time it was an appropriate suggestion for solving the problem.

In the morning Lisa waved off her mother's attempt to draw her into a formal introduction until she had been to the bathroom. Later as she hurried around getting ready for school, she watched the clock and chided her mother for her dawdling. I felt a great pride and tenderness for both of them, a sense of privilege for being able to share the deep affection and pride they showed each other. Over coffee, my eyes rested upon a small picture of Betty's dead husband. I hoped that he knew how it was with them. Betty's sense of loss had been turned into a sense of having received an unanticipated gift. For the half-formed, frightened stereotypes of Mongoloids were not Lisa any more than the shattered expectation of a "perfect baby."

But expectations can cause a sense of guilt as well as loss. Guilt comes from a sense of violating some societal standard, some commonly accepted norm. The guilt is insidious because it is not easily identified. The anguished *why?* which parents cry from their very souls is often taken as evidence of a sense of personal guilt. To me, however, these incessant whys are as much a search for real and relevant information as an expression of grief. What did I do to cause this? What is within me to make it happen? How can I plan for the future? Ruminations of past personal sin are quickly forgotten unless they are reinforced by individuals or social policy.

Unfortunately society seems to say, "You were supposed to have a perfect baby. You have violated our expectations. You have discomforted us. Put this child away. Or at least indulge your martyrdom quietly elsewhere. Don't bother us. Don't ask our resources. It is your fault."

When the social order tells you that your child is not valuable and not deserving, you have a dilemma. The human mind cannot accommodate such conflict. You can either internalize the assessment of the valued people and institutions or strive to change those standards. Chances are that either way most people will suffer some guilt. If you accept the assessment that society is right, you must give up on your child. If you think the prevailing system is wrong, you will have to confront powerful, valued people and institutions. Every time I have to compromise a principle, a free public education, for example, I hate myself for my inadequacy. In other words, I feel guilt.

On the other hand, it is not easy to challenge any existing authority. We do not like confrontations. We want to be nice, to have people like us. It is particulary difficult when those people who must be confronted are relatives, doctors, ministers, and others who have helped us in some way. It is difficult when those agencies who must be confronted are service providers and voluntary organizations upon which one must rely for service, and who are accustomed to providing in the manner they see fit for those who are at their mercy.

These organizations are used to thinking of themselves as advocates as well as providers, and have thus avoided any independent monitoring of their activities. This inherent conflict of interest requires either that they drop the provider role and start advocating for integrated public services, or that activists in the consumer sector must organize to watchdog their activities. But it is not "nice" to notice such elementary and essential incongruities. It certainly does not make one popular, and the risk is very great. Perhaps others do not feel such conflict, but I have been wounded daily for my observations and beliefs.

Other conflict and potential for guilt arises over the "cause" of a child's difference. Perhaps because the cause of Down's syndrome is known, Bob and Eleanor will not have to doubt themselves or face the pain and confusion of their other children. Perhaps they will know better than I did what to say. One day when Julie was four she threw herself at my legs, clasped them tight, and declared that she would put me in jail forever. I had broken her brother so that he could not walk!

Later, at five, she refused to say her prayer one night and lay glaring at the wall.

"I hate him," she announced with deep anger.

"Who?" I asked.

"I hate him. I can't help it." Finally she flipped onto her back and fastened a fierce glare on the ceiling. Pain bound her body tight. "I can't help it. I hate God. He made my brother crippled."

Even in her pain I could not comfort her. The authority of my own religious belief was too heavy upon me. One does not defy one's Maker. As I fumbled to clarify our theology, I fervently regretted having sent her to Sunday School where she learned that human sin caused imperfection, and that imperfection is a symbol of sin.

Later the same year, she came home from kindergarten and announced that she knew what had happened to Jeff. Her teacher had told her. I did not eat good food for my baby and that is why he turned out bad. It was an open, forgiving statement. Six years later she may still believe it. The college texts I have seen on birth defects are barely more accurate or less simplistic. Neither are the public-service announcements on television. I still do not know what to say to her, and she might not believe me anyway, in the face of the prevailing public education. And so for now I let it go.

Religious leaders must clarify the many associations of disability with sin. Otherwise this may color people's thinking and prevent them from intervening with their unreserved help and commitment. Or, they may turn from faith. Likewise I wonder what purpose can be served by having people believe that if one eats good food and does not catch venereal disease, one will make perfect babies. Hopefully some babies are spared birth anomalies because of this public education. Surely many mothers are stigmatized and suffer further pain when they bear infants with defects.

And we do not like to cause each other pain. That is one of the few hopeful notes in the story. Almost always the things which have caused me pain have been meant to be helpful, and perhaps served a good purpose at one time. Labeling and segregation were meant to protect both those "in" and those "out" while providing some service where there had been none.

Presently segregated services, whether Sunshine vans for transportation, special schools, sheltered workshops, or large residential facilities, tend to stigmatize people and separate them needlessly from others. Separate, "special" services tend to become single solutions rather than only one option among many others. Segregated services tend to postpone the day when public transit will be accessible to all citizens, when schools acknowledge *every* child's right to public education, when industry and business hire people with disabilities and make community living a viable option for everyone without the necessity of risking neglect.

And yet segregated services often began in someone's good intention. We cannot afford to mock good intention even when misdirected. But neither can we quietly accept the consequences when they are hurtful in some way; we cannot condemn the need some people have for status, power or profit. But it is wrong to be silent if these are bought at the expense of others.

Therein parents and people with disabilities have a dilemma. How can anger, frustration and pain best be expressed to create change? Anger, we are told, scares people and makes them bristle in defense. And yet some of us are angry. I get angry, for example, when I hear someone say, "There will always be those who need institutions." I used to think that large institutions could be "humanized." I used hours, months, and years of my life studying long time, I have changed my mind. I do not believe that large institutions are needed to fill even the most esoteric need, nor do I believe that one can learn the behaviors most valued by society or appropriate to the community within such places. Besides clinical concerns, there is a political issue which is even more important. People are simply safer from potential abuse in more typical settings where citizen advocates help to look after their interests.

And so when a highly paid administrator proclaims that there are always those who will need institutions, I say, "Yes, perhaps superintendents and government bureaucracies. *You* are the ones who benefit. Tell me who is this mystical 'client' who needs your warehouse? He is not my son." Our son, at the age of fifteen, needs to be catheterized four times a day. That still leaves us with a pailful of diapers. Jeff cannot get into his own brace by himself, cannot dress himself or get in and out of bed alone. But he does not need an institution.

Nor does he need a "skilled nursing facility." Several years ago the nursing-home industry fought against regulations that would require even a licensed practical nurse to be available at all times. Countless investigations have shown that too often medical auspices mean only high prices and control by largely absent doctors. The minute-to-hour care is often rendered by aides who have little medical training and who are as much victimized by an autocratic power structure as those they care for. No, as extensive as Jeff's needs are, they can be met by a competent, caring person within more normalized settings.

In fact, Jeff is doing well where he is. Most of his needs are met. But I need help. And I am not going to confuse that issue by finding him a residential facility and saying that *his* needs became such that this was necessary. I am depressed by the routine of his care, the never-ending struggle for service, and even the constancy of his company. I feel myself longing for some freedom, for a normalized life cycle which allows me to make commitments upon which I will not have to renege time after time because Jeff is sick and I must stay home; which allows me to leave a fifteen-year-old as other mothers do; and which would allow me to work, divorce, or save money for the future. When Jeff is grown I want to be able to confront myself and my freedom as other women do. I want to think that Jeff will have something to do with his life and a place to go. It pains me to think that he might end up in a bed in a storage bin for the rest of his days. It pains and angers me that I should be severely restricted forever for a moment in time and for so ordinary a thing as loving my husband and then committing myself to our child.

For Bob and Eleanor the cost of loving their child should not be so high; they will have an easier time. For one thing they will have some resource through the National Association for Retarded Citizens. (This should not be confused with the New York State Association for Retarded *Children* mentioned elsewhere in this book.) Recently parents of children with Down's syndrome have organized and pressured the organization into providing new materials and resources for those with that specific difference.

Furthermore, although the Association has spent years building segregated facilities as "models" for the public sector they have been able to re-evaluate their course. For example, the public sector has been slow to emulate their models or to include people who are retarded. As more and more public funds become available to private agencies, this creates a peculiar situation. The government begins to "monitor" and private, professionalized agencies are expected to provide hard service. Even many of us who hate to see "government do it," are more comfortable with the public sector providing hard service like public schools and the *citizens* watch-dogging the action. We have seen how badly the government monitors nursing homes and Medicaid services, for example. We have seen how the government, at all levels, has grown fat on "soft" service like monitoring and administrating; and we have seen our children without conflict-free advocates. NARC is said to be moving out of the kinds of service which are ordinarily provided through other agencies and moving into advocacy. And that is good news for new parents.

Many parents and professionals in NARC are studying normalization and combining this with advocacy. That is, they are encouraging every act, word, and service which is typical or valued in our society as it relates to people who are retarded, and they are discouraging every act, word or service which devalues, needlessly separates, or discriminates against those with retardation.

Bob and Eleanor will have the benefit of materials of substance and beauty like *The Gift of Martha, To Give An Edge* and *The Diary of Nigel Hunt*. It is noteworthy that these books were created by parents, professionals, and a young man with Down's syndrome respectively. They are evidence of what each of us can give to each other.

They will be able to subscribe to *The Exceptional Parent Magazine* wherein parents, professionals, and people with disabilities speak out, usually in mutual respect if not in agreement. But most of all, they can learn from its pages and from the struggles and joys of those who contribute. This magazine and advocacy centers like Closer Look, The Center on Human Policy, The Training Institute at Syracuse University, and the National Center for Law and the Handicapped help to teach consumer-advocacy skills and to bind people together in strength and understanding.

But Bob and Eleanor may have problems, too. For when those upon whom one must depend for education, health and dignity do not value a child, misery is not far behind. And not all people do. Dr. William Bronston, in the book *The Mentally Retarded Child and His Family*, makes this point by telling of a mother who, for two years, had to dig feces from her child's rectum for evacuation of body waste. A medical student could have recognized the problem Dr. Bronston assures us. However, the child's pediatrician, "highly respected in the medical community," failed to do so or to recommend help even upon confrontation by a demoralized mother and an undernourished child. The problem was solved surgically when a doctor with different attitudes intervened.

Many people are tempted to think that the condition of our children is wholly dependent upon technology; that medical or educational advances and research will solve all of our problems. Nothing could be farther from the truth. Jeff has suffered needlessly because someone failed to use a tape measure or an ordinary, work-a-day opthalmoscope. As Dr. Bronston puts it, "If the ideology behind the technology is unworkable, the technology will not work." In other words, neither opthalmoscopes nor integrated settings will work if people's beliefs and attitudes are negative toward our children.

Some medical advances have been made in the treatment of children with spina bifida in the fifteen years since Jeff was born. But I believe that Jeff would have done significantly better if he had had full access to the resources available within our community at the time. And that accessibility has not changed very much for others to this day. At our last local spina bifida meeting a young mother complained that Mrs. Braintree had upbraided a therapist with, "Why are you wasting your time with her?" The mother was infuriated that someone else's child should be devalued like that.

The therapist had replied, "It's my time."

That took courage. Hopefully parents as well as professionals will have this kind of courage as we work together. That will be one of our responsibilities in the recently organized Spina Bifida Association of America. It will be a challenge to promote the value and respect of our children, for without those, all of the research and technology in the world is worthless.

We will want to reach out to new parents with friendship, information and emotional support, not with injunctions either to joy or grief. This will mean listening with respect and humility. Hopefully we will be able to provide a safe atmosphere for parents to express their feelings, whatever those feelings are.

We will need to learn the skills of advocacy and to teach our children to speak on their own behalves. That will take courage and trust for their needs will often conflict with ours.

We will have to look beyond ourselves, not only to those organizations which can help us to our goals, but also to forgotten people. At a recent medical symposium, statistics were given from various mortality charts on those children who were selected for treatment and those who received little or none in hope they might die. No one asked what happened to those who lived on. No one asked if their lives were not significantly more limited. No one asked if their parents agreed or even knew of the experiment. No one asked whether parents or doctors have a right to withhold beneficial treatment and thus sentence a child to increased disability. I do not know if it is lack of caring or lack of courage; I am pained that we do not ask.

An editorial in the prestigious *Developmental Medicine and Childhood Neurology* (1975, 17, 561, 562), complains that in saving children what initially appears as success may later show "poor scholastic performance, specific learning disability, or behavior disorders." The author calls upon physicians to correct Nature's errors in allowing defective fetuses to be born alive, and cries out against "moral, religious or political illogicalities" which could "shackle" the actions of the medical profession.

Is our experience with Jeff an exception? I think not, judging from my contact with parents all over the United States. I think not, considering the way many people feel toward "defectives." So far our organization has not made it clear, that at some point, decisions of life versus death and rehabilitation versus neglect are social and moral matters, not medical matters. That will take courage.

But courage can come out of an individual's pain and out of social injustice. It can come from caring about what happens to one's own child, and what happens to others.

This is my story, not Jeff's story. It tells only what I need to say and what I think other people need to know. It represents part of one woman's experience in loving one particular child.

Only Jeff could tell us what more than two dozen operations on his body have meant to him, what it is like to stop breathing, or how he feels the difference in the hands of condescension and the hands of caring. Sometimes he has told us with his behavior, someday he may tell us in words which can be shared.

A few days ago Jeff asked, "Mommy, am I retarded?" I was dumbstruck, but managed to say, "Well, yes. Yes, Jeff, I guess you could say that; but you're also smart." Then I saved myself with, "Why do you ask?"

"I was just wondering," he mused.

"Well, yes. I guess the answer is yes," I said quietly resolute. "Do you know what it means?"

"It means I don't go to Glendaal School."

What an extraordinary boy we have. Retarded because he doesn't go to the public school, not because he scores 36 on a Binet test. There is sense in what Jeff says. Sometimes we have made people crippled, retarded and handicapped by our definitions, tests and physical and social exclusions. Sometimes our response to their difference has created the only deep and abiding limitation they feel.

I am profoundly glad to know Jeff. Once I heard Ramsey Clark, former Attorney General of the United States, say that his retarded daughter taught him greater truths than all of his travel and any of the great and famous people he had known. I understand that.

Jeff is neither my burden nor my chastisement, although his care requires more than I want to give at times. He is not an angel sent for my personal growth or my future glory; he is not a punishment for my past sins. He is a son.

Our needs do not always coincide so that I am not always a perfect mother or even a reliable advocate. We love each other. We enjoy each other. And we are friends to each other. That is why I have chosen not to sublimate my anger and my pain. The love and the friendship Jeff and I share is why I ask others to work for change, because we cannot do it alone.

—The End—

Sticks and Stones
The Story of Loving a Child

Elizabeth Pieper

Many parents of disabled children have written autobiographies. Few have written the way Betty Pieper writes. Her story communicates as much about our society as it does about the Pieper family. We come to know both in an unforgettable way. Betty Pieper writes with warmth, determination, even anger.

When she first found out that her son was disabled, Betty Pieper knew little about disabilities. She knew even less about the depth to which our society discriminates against people who have disabilities. She quickly learned about both. And she learned one other thing as well. She learned how to advocate for her child, for all people who have disabilities, for all people.

"Sticks and Stones will break my bones but names will never hurt me." Or will they? Betty Pieper admits the hurt that accompanies prejudice and discrimination. Yet this is no account of hopelessness or pessimism. For Betty Pieper possesses what all change agents must: optimism about our essential humanness.